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ABSTRACT

This student manual, part of the Family and Community Health Through Caregiving program, focuses on the impact of children with birth defects on families, and the ways families cope with the needs of these children. Topics include: (1) genetic causes of birth defects; (2) how the community and individuals can help families with special-needs children; and (3) how some families and individuals react to the special needs child. Case histories present the experiences of families and individuals involved with special needs children. (CJ)

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ED191815

Starting A Healthy Family Series/
Family And Community Health
Through Caregiving

Families With Special-Needs Children

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Contents

Five Families 2
Jenny MacLean 3
Talking With Dr. Neil Macintyre 6
Neil and Donna Hobson 10
The O'Mally Family 14
Talking With Dr. Robert Cooke 18
Geri Gable 20
Bill and Margot Kaldma 23
Range Of Retardation 29
Birth Defects: Why Do They Happen? 30
Inheritance: The Biological Connection 33
Parents And Their Children's Health 42
Glossary 44

"We must learn to understand and help those who are touched by birth defects, both the children and their parents, for theirs can be a hard and lonely road if traveled alone."

Parent of a birth-defective child

Betsy Cole

There are a number of efforts that have gone on throughout the length and breadth of the United States in order to talk about the quality of life of our people. And every time we start doing this, one thing becomes very clear: the loss in human fulfillment, the loss in human potential, is extremely great. This is occurring at a rate that is much faster than we can keep up with as a nation, and much faster than we can tolerate if we are to continue as a great nation in the truest sense of that word. For without fulfilled people, how can we consider ourselves a fulfilled society?

In 1970, the American Medical Association began looking at this problem from a medical point of view. We knew that people were coming to physicians in massive numbers, and that these numbers were increasing each year despite our advances in diagnosis, treatment, and cures. What became clear as we looked at the problem was that people were coming to physicians not because of viruses, bacteria, and metabolic problems; not because of lesions in specific organs. Rather, people were seeking help because of their inability to cope, because of problems in their life style, because of problems in their orderly growth and development.

This meant, then, that we had to take a good look at what we mean by health and health care. While medical care is

an extremely important part of health care, health is much more than medical care alone. Health means the positive participation of an individual in all the various environments that surround him or her — the physical, social, psychological, and financial conditions in which a person is born and through which a person proceeds with the continuum of his or her life. We must, therefore, place health care within a social, environmental, and educational frame of reference in order to feel that we are developing a sound program of health care. Professionals whose efforts have been fragmented and whose expertise has obeyed strict and traditional boundaries *must work together*. This includes physicians, educators, social scientists, and all others in the human service field, as well as the people they are privileged to serve. No matter what else we are doing, our overriding objective, whether stated or hidden, should be to improve the *quality of life* of our people. To put it another way, we should constantly strive to promote the total human condition of our people.

To achieve this, we must look at the subject in total. We must place each person in the framework of the quality of his life in its many aspects. We must realize that in order to talk about having generation after generation born healthy and living healthy lives, we have to start from the very beginning by thinking of life as a continuum. We must realize that this is a multigenerational issue, that the quality of life of a baby begins with the birth of its parents and continues to influence the quality of life of those who come long after this new person has himself ended his own journey through life. Perhaps most importantly, we must realize that each successful newborn baby presents himself essentially by saying to us, "Here I am, a member of the family of man. What now?" The answer to that question is up to you. It is up to all of us.

Effie O. Ellis, M.D.
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Family and Community Health Through Caregiving is a new kind of health education program that views health with a fresh perspective: health means more than biologic fitness. It is a "measure of each person's ability to do what he wants to do and become what he wants to become."*

Good health results from the decisions we make, decisions that ideally promote our physical, emotional, and social well-being, and connect us to our families and communities in healthy ways.

One goal of this series of books is to encourage people to plan for the future by making choices that improve chances for a satisfying and healthy life.

To make decisions that have positive health results, we must understand:

- why we act in the ways we do.
- how our families and communities can influence and support us.
- how we can make decisions that are right for us by looking at alternatives and their consequences, and then planning wisely.

We have a better chance of making healthy choices when we have thought through our own behaviors carefully.

*Rene Dubos, "Health and Creative Adaptation," *Human Nature*, January 1978, p. 74.

In *Families With Special-Needs Children*, parents of children with birth defects talk openly about the pain, frustration, and burdens they faced, the rewards they discovered in raising children with special needs, and the resources they found or did not find in themselves and others for coping with their new responsibilities. The causes of birth defects and how inheritance works are explained, to help you understand both the risks involved and ways to prevent birth defects.

But this is only part of the story. Two other books, *Starting A Healthy Family: Choosing Parenthood* and *Families and Futures: Helping Self and Others* provide other perspectives on the rewards and responsibilities of parenting. *Starting A Healthy Family: Choosing Parenthood* explores the choices and life changes that people face when becoming parents or deciding whether and when to become parents. It includes information on prenatal development, the first nine months of life. *Families and Futures: Helping Self and Others* looks both at the ways communities and individuals can help children with special needs and their families and at the steps parents can take before and during pregnancy to provide a healthy and safe environment for their child.

A glossary is provided with this book. Reading straight through it will tell you a great deal about parenting and pregnancy, and help you to know what information anyone should have who is thinking about becoming a parent.

Five Families

2

During the next hour, about 7,200 babies will be born into the world. At the moment of their birth, the infants will be more like each other than they will ever be again. From that moment, the particular world they live in — their family, neighborhood, and society — begins to influence their growth. While they will continue to have many similarities, their individual differences will also be developing.

Approximately seven percent of children born each hour — about 360 of them — will be born with birth defects. Their parents will have to adjust quickly to a whole series of unexpected demands, and absorb a new understanding of what the baby will mean to them. "Handicapped," "brain-damaged," "retarded," and "birth defected" are some of the terms used to describe children born with defects. The meaning of these terms vary, but we can say that all persons born with defects have *special needs* that affect them as well as their parents and others around them. These needs may be physical, mental, or emotional, or a combination of all three. Some children with special needs will be able to overcome their handicapping situations as they grow older, while others will be severely affected for life.

In our society, we have tended to group "like" people together, believing it was for their own good. We have tended to set people aside who were born with defects or who acquired physical or mental characteristics that were considered abnormal. But we are beginning to understand that life is varied indeed, and to value diversity among people. As people with special needs move into the mainstream of our society, becoming more visible and more involved with the rest of society, we are beginning to see that there is no such thing as a " typical" person, no one kind of person that is what we all think we should be.

For people who have birth defects, it is a relief that the rest of society is beginning to look past their problems, which make them different, and to see that their needs and feelings, their joys and sorrows, are very similar to our own. Accepting them as people who have much in common with others, but who have problems other people don't have to face, will make their lives and the lives of their families easier.

But this does not mean we should lose sight of the enormous physical, emotional, and social limitations suffered by people with birth defects and their families. Fantastic effort and courage are needed to cope successfully with the problems stemming from birth defects. Even while we learn to accept birth defects, it is still critical to try to prevent as many defects as possible.

In this section, we look at five families who have children with birth defects. These case studies are true. They were chosen to show how families react to the birth of a special-needs child, and to suggest the variety of ways in which people adjust to raising children with birth defects.

In some instances, the photos do not represent the actual people in the case studies. This has been done to protect the identity of those wishing to remain anonymous.

CASE STUDY

1

Jenny MacLean

"Never dreaming, never dreaming . . . ."

Jenny MacLean was 29 years old and had just moved to North Dakota when her first child was born.

I had a threatened miscarriage when I was pregnant, and the doctor told me not to be concerned about it, that lots of women had bleeding during pregnancy, and he hospitalized me. But he convinced me so thoroughly that it was a common occurrence, that it never, never entered my mind that it might mean something about the baby.

We came to North Dakota where my husband was starting a new job. We were living in a borrowed apartment, and in the back yard was a beautiful apple tree. And it was full of apples. It was September, September 24. I looked at that tree. The man who owned the house was an old Italian man who had pruned that tree so that it was a thing of beauty and it was bearing these apples. And I kind of clung to that tree for a couple of minutes. And my husband said, "What are you doing?" And I said, "I don't know. I'm afraid." And somehow, that tree was so beautiful and so perfect, and I just sort of stood there holding it.

We went to the hospital and I had a very long labor, 26 hours. And the baby was delivered. It was evening. And I saw the baby. And the doctor said I had a son. I must say that I was very pleased to have had a son, because I was one of three daughters and had always wished I'd had a brother. I remember feeling so great that my husband called our parents and said that we had a son. And that was a really wonderful feeling.

They brought my son to my room. And they put him in my arms and I held him. I looked down at him and I said, "Well, you're kind of a funny looking thing, but maybe you'll improve." I remember saying that to him. Because I thought that he was kind of funny looking. Never dreaming, never dreaming.

The next thing I knew, it was morning. My baby had not been brought to me, but I didn't know enough about hospital procedure to realize that. My door opened and my husband came through it just wildly crying. And it so unnerved me, because I had never seen my husband cry. Never. And to hear him sobbing in such an uncontrollable way, I just couldn't imagine what had happened. And he threw himself across my bed and sobbed wildly. And I said, "What's wrong? What is it?" He finally said, "He'll never be all right. He'll never develop." I said, "Who?" and he said, "Timothy. He'll never — he'll never be normal." And I said, "What are you talking about?" And he finally got it out; the doctors had been waiting for him and had told him that our son was a mongoloid child, and that he would never develop and be normal.

His parents had been planning to fly up to see us right after the baby was born, so I said, "When will your parents be here?" And he said he had just called them. "They're not coming." His parents had told him not to look back at what had happened. They said to close the door and never open it again — never look behind it again. His parents seemed ashamed and did not want to talk about it.

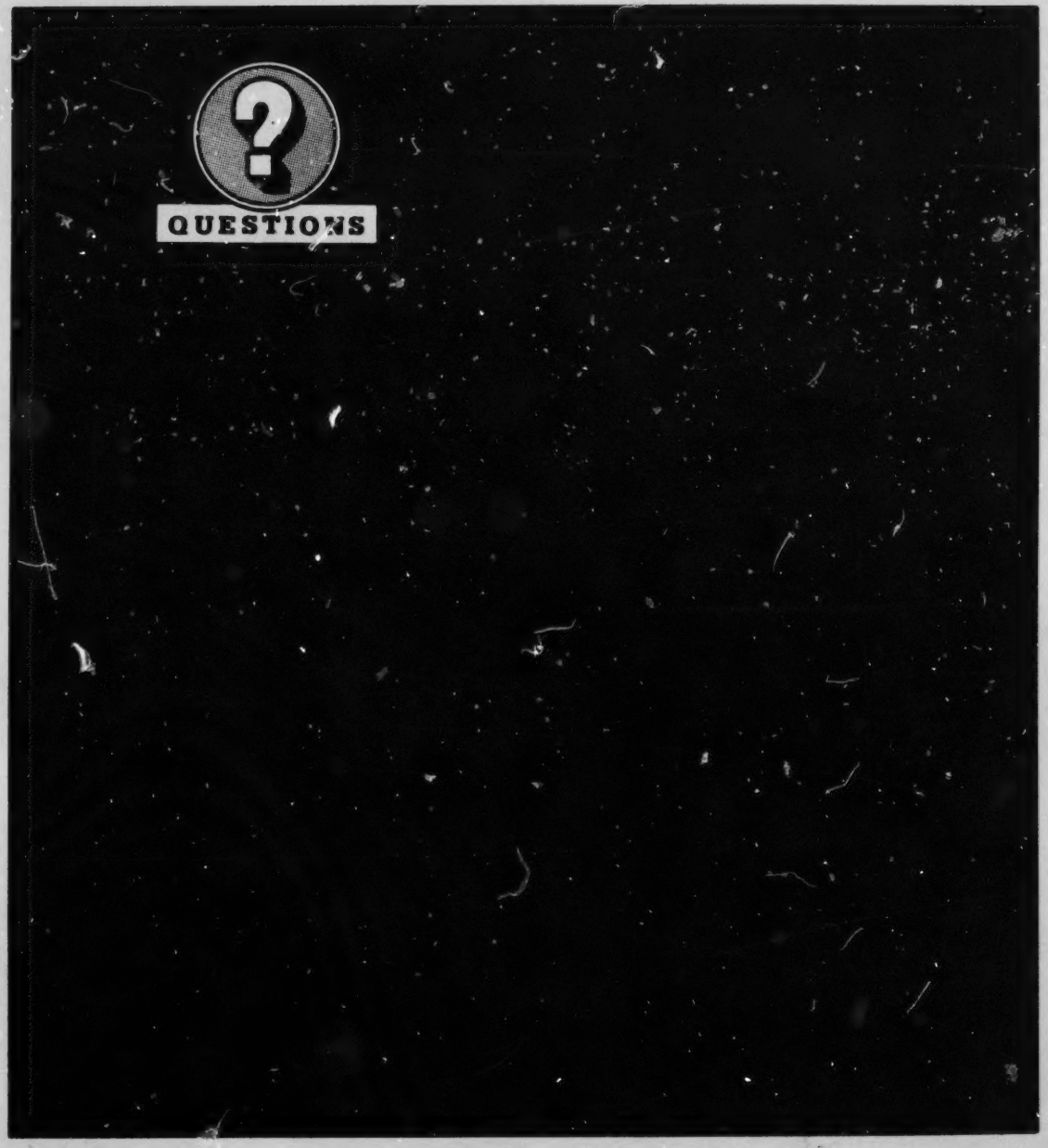
"Moonstone" by Isabel Levine-Jones

Well, they made him leave because they had rigid visiting hours. And then I realized the enormity of what had happened. I got out of bed, and I walked over to the window and I thought, "How am I ever going to deal with this?"

The pediatrician came in and he said, "I have examined your baby carefully. I have given him every test we know of. I can tell from muscle tone tests and other tests I have given him that he will never develop properly. He will be severely retarded all his life."

I hated all the things the doctor was saying. I hated the graphic description of how the baby's toes were slightly webbed and how his fingers were abnormal. I thought, "How could I have given birth to such a child?"

I think that from the time my husband came into my room crying the way he did, I just felt inadequate. I mean, I had no idea what this baby was going to mean to him. He had never said.



Talking With Dr. Neil Macintyre

Dr. Neil Macintyre is a genetics counselor at Case Western Reserve Medical College in Ohio. He has a great deal of experience in talking with parents of children with serious birth defects. In the following article, he describes what he believes are the normal first reactions all parents have to the birth of a special-needs child. Then he suggests some ways he feels people can help these families.

John McGannon

One of the most meaningful and personal experiences in human existence is that shared by a husband and wife when they produce a wanted child. Such a child, purposely conceived with love and cradled in hope, represents to its parents a special kind of extension of themselves into the future. The expectation is that the child will be a combination of the best in both of them. Naturally, therefore, such parents look forward to the birth of a bright and beautiful baby, which they can present to themselves and to the world with pride.

Because of the intensity and the personal nature of the parents' feelings, if that child is born mentally retarded or otherwise defective, the emotional impact on each parent is tremendous and frequently overwhelming. The first and almost universal reaction of such parents is shock, followed by a period of denial or rejection of the child. Then, as the reality of the situation becomes apparent, emotions such as anger, frustration, and despair are very strong. The majority of such parents whom I have counseled have admitted that they have hated the child during this initial period, hated what it is doing or will do to their lives, and have wanted it to die.

Such frightening feelings generate a tremendous amount of guilt in the already tragically suffering parents, because they feel that it is unacceptable to have such negative feelings about their own child. The majority of parents of birth-defective children are denied the opportunity to express their feelings openly, even to each other. Instead, they continue to pretend that they are accepting the situation well, while inside they hurt badly.

Unfortunately, a less than normal child often is viewed with fear and abhorrence by many people outside the couple; and these reactions from others can create an additional burden to the already distressed parents. Relatives of the child, such as grandparents, are directly involved and personally threatened or disappointed. This places a tremendous strain on the families. Friends and associates of the family usually feel embarrassed and uneasy about the situation, and in their attempts to express compassion more often than not end up saying the wrong thing. They may also feel awkward and avoid any mention of the child to the parents. They may even remove themselves from the situation by avoiding the parents, pressing the couple into an even greater isolation.

Even professionals, such as physicians and nurses, are too often less than helpful, as indicated by the following quotation from a mother describing her hospital experience immediately following the birth of her abnormal child:

> *Hospital personnel did not know how to handle their feelings. Doctors and nurses did not know what to say to us. People could not acknowledge that anything had happened to us. The baby was the focus of everyone's concern and attention, and we were made to feel guilty if we expressed anything but acceptance and affirmation from the very beginning.*

It seems important to me that professionals recognize that when a defective child is born, something shattering has also happened to the parents — something that puts these new parents in a position of being patients themselves. They *need* help. At the Yale-New Haven Hospital in Connecticut, parents of birth-defective children routinely are given daily counseling sessions. When the mother leaves the hospital, outpatient care is made available to the couple. It is my hope that such services will be started and continued in a wider range of professional settings for such people.

It has been my experience that there are significant differences in the way in which husbands and wives handle this catastrophe. Most wives seem to recognize more readily the need to talk about their frightening feelings with their husbands, whereas the husbands usually prefer to deny the situation and do not want to discuss it. I believe these differences stem from the different ways in which males and females are raised in our society. For the most part, girls are given the freedom to cry and grieve more openly, whereas boys are raised to be strong and silent. Furthermore, a major situational difference is that the wife is ordinarily "trapped" at home with the defective child, while the husband has the privilege of getting away by going to work. In fact, it is not unusual for husbands to start spending longer hours at work after the birth of their abnormal child.

These differences, as well as many other factors, tend to lead to a deterioration in the communication between husband and wife, and place a tremendous strain on the marriage relationship. One of the more pronounced ways in which this deterioration is witnessed is in the decline of the sexual intimacy shared by the couple. Anxiety is a tremendous deterrent to sexual intimacy at any time; when anxiety is associated with the reproductive process itself, it is doubly devastating. A recent informal survey of the family situations of children in

schools for the retarded and handicapped in a large midwestern state indicates that the rate of separation or divorce among parents of abnormal children is approximately 75 percent — more than twice the national average.

The facts and figures I have presented are tragic and distressing indeed. Why do most families of abnormal children suffer so, and what can be done about it? I believe that to help these parents and their children, we need to become more aware of their real feelings. Our most fundamental and widespread error is that too often we treat these parents as if they felt the way we would like them to feel, rather than the way that they actually do feel. For example, the traditional attitude toward such parents is one which says, "Of course you love that baby." When such an attitude is expressed at a time when the child's parents are struggling desperately with the realization that they cannot at that time love the child, it adds an additional burden of guilt to their already almost intolerable situation.

Not all couples suffer to the extent I have outlined above; in fact, I know many couples who have not experienced this particular pattern of response. But it is important to note that in these cases, there has been professional counseling of some sort; a large amount of support by family or close friends with whom the couple has been able to discuss their distressing feelings freely and honestly; or a deep ongoing commitment to religious or philosophical beliefs that help to guide them.

However, we need to realize that many parents do have some frighteningly negative thoughts about their child when he or she is born defective in some way. We must also realize that, for them, such reactions are normal under the circumstances, and require our understanding and compassion rather than our rejection. Only through such understanding can we give these suffering people a chance to express their feelings honestly and to know that they can be accepted as normal. My experience with many such couples indicates that only when they can be helped to feel good about themselves and their feelings are they in a position to accept their abnormal child with anything close to the degree of love and support that all such unfortunate infants desperately need. Hopefully, through such acceptance the couple can also have the increased love and strength to deal with the ongoing demands of raising their special-needs child.

ACTIVITY
Mirror Image

CASE STUDY

Neil and Donna Hobson

"It's just the idea of accepting it."

Neil and Donna Hobson are in their mid-thirties. Their first child, a son, is normal. They have two sons who were born with birth defects. Jeffrey has a defect that doctors cannot identify specifically. It shows up as a weakness on the right side of his body. Joshua, the youngest, was born with very little brain tissue, and is profoundly disabled. In the following interview, the Hobsons talk about their response to the birth of Joshua.

Neil
Josh, well he's eight months now and about three months after he was born, Josh's pediatrician just had a gut feeling about him that something was not right.

Donna
In fact when he was born, his head and his body were the same size, he looked like a little midget.

Neil
The pediatrician sent him down to Yale, New Haven, to have a test done, and it turned up very negatively.

Donna
Most of his brain just isn't there and he's never going to function normally. He's never going to walk, he's never going to crawl.

Neil
And the only brain tissue that he has, just about, is at the back of the skull here where all the vegetative processes are: sleeping, the growing, the eating type of things — that's all that's intact, everything else is just fluid up there.

Donna
And I got very upset, very upset and I cried, it was just a very earth-shattering thing.

Neil
I guess my feelings at the time were not, were not like Donna's. Donna was really distraught about the whole thing. I wasn't, and I think I was more concerned about how Donna was feeling, more than actually if there was something wrong with Josh.

Donna
I was just wondering what happened, what went wrong, why me? What did we ever do to hurt anybody? I don't know if those are normal feelings or not, but I, it just goes through your mind.

Neil
One of the things that I think helped us, I think it was just plain arrogance — and arrogance that I have seen so many people do crack, so many people do fall apart under a stressful situation, that I just wasn't going to let it happen to us. And also there is really nothing that is, is that worrisome, there really is nothing that, you know, that terrible that can happen that I feel that we can't overcome.

Donna
Well, I do have different feelings. I worry a lot. I'm a worrier, and he'll look at me and he'll say, "What good does it do to worry? What are you worrying about, what can you do? You just sit there and worry and that's not helping the situation at all." So actually, why worry?

Neil
I do know of families that will blame the one spouse or blame the other spouse for the way the child has turned out, and I'm sure this is one cause of why you have families break up. Because if there's a handicapped child in the family and, you know, "That's your child," especially the wife, you know, and the husband might say, "Well, you're the blame because you gave birth to the child." And I think the big thing is that you've got to let your partner or your spouse know exactly where you are in the situation, otherwise you get into the "it's your fault" type of thing.

Henry Felt/WORKSHOP FILMS

Donna
But it's just the idea of accepting it, because as I say, for three months the kids were in school and I was alone every day with Josh. And it was just really great, and I really enjoyed it, you know. And then finding out, you know, and it was just, just an awful feeling.

Neil
There was a big tendency when people did find out that there was something wrong with Josh and with Jeffrey, the big question always was, "How's Donna doing, how's Donna taking all this?" Yeah, "poor Donna this," and I'm not looking for sympathy at all, but it was always directed toward Donna, and I think that would be a normal tendency in any family, that the wife is supposed to go to pieces and the husband is supposed to be the rock.

Donna
Neil has very strong faith, he really does, he has really strong faith and I think that pulls him through a lot.

Neil
Yeah, there's an element of religious faith in there, a lot of it is, but it's not a crutch type of thing, it's just something I believe in, it's a belief in man that he can overcome any obstacle that he really wants to. It's that old story of Job in the Bible. He was a very rich person and he was plagued with a whole bunch of leprosies, his farm got wiped out, he was starving, he lost everything. And people thought it was God punishing him, and he would never turn against God.

Donna
I just kind of coped with it and said, "Well, it's a problem that can be overcome." And that's what we're doing, we're doing the best that we can do to handle the situation.

Neil
I think I was more sorrowful for Donna, because I think she had more expectations for Josh than I did. I wasn't sorrowful that he's never going to be a football player or a great student, or anything along those lines. There is a lot of important things, a lot of good things in this life that he's not really going to experience, which is too bad, but hopefully he'll experience those things he can to its fullest and he'll enjoy those. Now if all that is is just rolling over or sitting up, that's enough for us, because that's the only expectations we have for him, and I think that took a long time for Donna to kind of finally accept.

Donna
I didn't tell my mother until three months after I knew about it; it took me a good three months to adjust to it myself. I had to accept it first and then I told her. My mother still can't accept it. She'll say, "You still got that baby with you." And this upsets me. "That baby," I says, "That baby's name is Joshua, he's got a name, please call him that. She still doesn't know his name, it's "that baby." And that upsets me. Because he's not a normal child and, you know, he's severely handicapped, it's "that baby;" his name is Joshua.

Henry Felt/WORKSHOP FILMS

Neil
Joshua is still a person to us, regardless of what he will not be able to do or what he will be able to do, you know. He still can be happy, and he still can achieve some sort of personal satisfaction. He still can achieve to be the best possible person he can be, we just kind of really believe that.

Donna
It will be very difficult for us, like when Josh gets older to carry him around, and he's still going to be a baby when he's five years old. And we realize that.

Neil
When he's five years old, he's going to be an infant still, and there's just no way he's going to progress. And when he's ten, he's still going to be an infant. You know, he's going to grow because he does have that function. You know, he will be like 60 pounds or something. In fact, he'll probably be more, 'cause he won't be getting the exercise.

Donna
We treat Josh just like a normal baby so everybody else on the street does. In fact our neighbors will do anything for us. I mean, they're just very — all I can say is we're just all really friendly people. They don't turn away, in fact they lean toward us. They all hold him, and we're not looking for their pity and they know this too. I think that's very important. I think if we went around hiding Josh from the world — like I know of cases where they do, where they just hide him. But we bring him out in the open, you know, and just take him everywhere with us. We're not hiding him and we're not ashamed of him. We love him and we want everybody else to love him.

Neil
Okay, we do have a child who has a handicap. That was one thing that's changed. But we still had our health, we still had our good friends, we still had our jobs, we still had our house, whatever, all these types of things. Nothing of that has changed.

CASE STUDY

The O'Mally Family

"Sometimes it's really hard to be patient."

There are nine children in the O'Mally family, and two of them — Johnny and Mary — are mentally retarded. They were born with a rare form of Down's Syndrome (Mongolism) that is hereditary.

Johnny, 19, has lived in an institution since he was a baby. Mary, who is 13, was raised at home until two years ago, when she went to live in a residential school for retarded girls.

In the interview that follows, their older sister Peggy talks about her family's life; about the reactions of her parents, brothers, and sisters to Johnny and Mary; about the family decision, as Mary reached adolescence, that Mary's needs could no longer be met at home.

I don't even remember my brother Johnny being at home. He was sent away when he was an infant. It was my father's wish that he go away, and my mother agreed to that. There were no arguments about it. I never questioned it, and no one else did either. We forgot. It was like he was never there.

When my sister Mary was born, I remember some commotion about her birth. I was eight at the time, and my mother didn't come home from the hospital for a long time, maybe 10 or 12 days. That seemed very strange. It wasn't until a year later that I was told Mary was born with a birth defect. My parents didn't use those words, exactly. They said Mary was a special baby, that she was different from the rest of us.

Again, my father wanted the baby to be institutionalized. But my mother said no. She wanted Mary at home. I think there was a big conflict between my parents.

My father has a brother who had Down's Syndrome, and I think he carried a lot of guilt feelings with him that perhaps there was some genetic factor involved with my brother and sister. And I think he was pretending that if the children were away, the problem didn't really exist. That's what he did with Johnny, and I think he wanted to do the same thing with Mary. But my mother won out with Mary and I'm glad. I enjoyed having her at home.

As a baby and a young child, Mary didn't seem to require any extra special care. She was like other babies, fun to play with.

We all had to help take care of Mary as she was growing up, and she grew up slowly. It took time to teach her how to dress herself, and tie her shoes, and things like that. You had to let her do it for herself. It might save five minutes to tie her sneakers for her, but we knew she had to learn how to do it for herself. Sometimes it was really hard to be patient.

I think I first realized that Mary was mentally retarded when I was nine or ten. I had a hard time dealing with it. I wouldn't talk to anyone about it until I was sure how *I* felt. When friends used to come to the house, they would meet Mary and it would be awkward. It was very difficult for me to learn to deal with.

I think we all pretty much went through the same thing, trying to understand what Mary's condition really was, getting used to the reactions of people outside the family, having friends learn to accept her. When the older ones in the family started getting married, it became an issue, I know, with each of them. "What if my fiance doesn't accept Mary? What will it mean to me?" Mary is very important to all of us, and we all feel that if you can't accept her, well, we're sorry, but we can't accept you.

When I was living at home and going to high school, and my mother would ask me to go to the supermarket or something like that, I would take Mary with me. If she wanted to pick out a birthday card for

John McGannon

someone, I'd go to the store with her. And if I had an appointment with the dentist, chances were that she did too, and we'd both go. This was the pattern my mother set. We saw my mother bringing Mary everywhere with her, and I saw my older brothers and sisters doing it, so when I got to an age where I could help, I just followed suit.

My father's attitude toward Mary always has been different. He responds to Mary inside the family like she's just one of the gang, but he doesn't really like to be seen in her company by other people. In public, he withdraws from her.

It's all been a strain, I know, on both my parents. It's taken a lot of their time. A lot of pressure was put on my mother to send the children away, something she didn't want to do. And they both had to give up a lot of free time. When my mother would spend time with Johnny or Mary, my father would spend time with the rest of us, seeing that we got all the care we needed, that we were not tearing the house apart, or killing each other — things like that. So I think that my parents spent a lot of time apart, and it must have been hard on their marriage.

You know, children with Down's Syndrome are not all alike. Some are very severely retarded and have physical defects as well. Others are less seriously affected, and Mary is one of those. She's a healthy child, even though she's smaller and thinner than the rest of us. She can feed and dress herself. She can read and write. She can dial a

John McGannon

phone, she can tie her shoes, she can play ball, she can swim — that's her favorite thing. She can't ride a bike, and that's a big disappointment to her. Her sense of balance isn't good enough, but she can ride a three-wheeler.

She has trouble with finer hand work. If you were to ask her to put beads on a string, she would have a lot of trouble with that. But if you ask her to put balls in a barrel, she can do that. Mentally, her teachers think she's still climbing.

As we all got older, we had less and less time to play with Mary, and I think she began to get lonely. She went to school regularly, to a special classroom, and she learned a lot. She took the school bus by herself and was getting to be pretty independent. But she had reached a kind of stalemate at that school. It began to get dull for her, and we all felt there was nothing more that the school, or the family at home, could do for her. We felt that if we could find another school where she could learn a trade or something like that, it wouldn't be fair to hold her back. Her teachers recommended a boarding school, and after a lot of looking, my parents found a very good one out in the country. We called it her college, and Mary was very excited about going away to college just like the rest of us.

We were all asked what we thought about her going to school, and whether we thought it would be a good thing. We all talked about it. Once Mary did go away, my parents felt freer. I think they're really enjoying spending more time together.

Mary's been living at this school for two years now, and it's just doing really great things for her. It was hard for us to see that she was growing up, because we always had a tendency to keep her as our little baby. At school she takes care of herself.

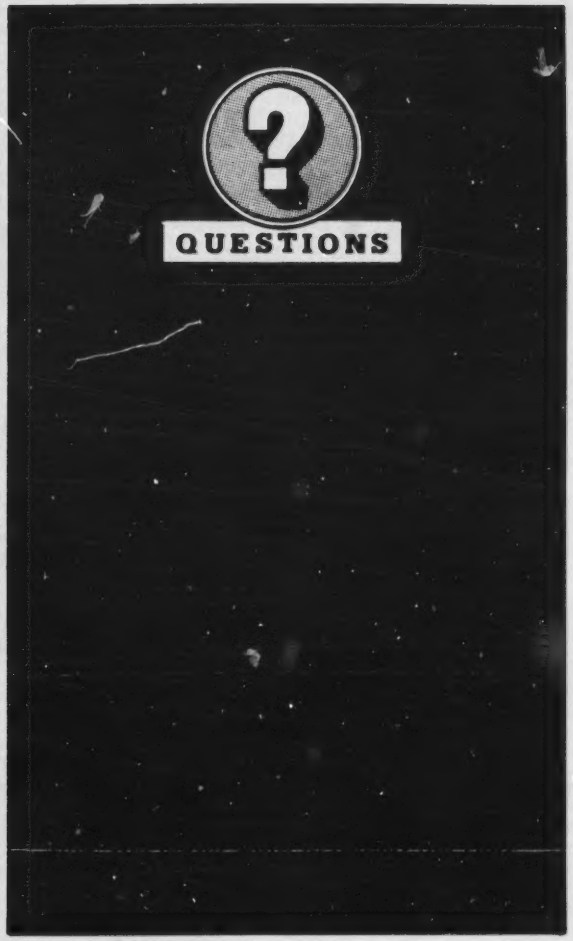
When she went away to this school, Mary had just started to get her period. She began shaving her legs while she was there, and I thought I was going to die when she came home with a little electric razor. I thought, this can't be Mary, my little sister.

Even though Mary lives at school most of the time, she's still very much a member of the family. With Johnny, it's a different story. We don't know him. He's not with us very much. My parents visit him, but we don't. I guess we could, but we didn't when we were younger, so — I don't know. I think it would be awkward going to visit someone who is in your family, and yet not knowing him, and he not knowing you.

I don't know why we have these two people in our family. We just accept that this is the way it is without blaming anyone. My parents are both very religious, so I know that they look at it as the will of God. And that makes it easier for them. I don't think that all my brothers and sisters have a very religious sense; we each have to deal with it in our own way. But we're all very open to it.

We do worry about our own genetic make-up, and we are all concerned about having a child who has Down's Syndrome. It's a tough thing to deal with.

John McGannon



Talking With Dr. Robert Cooke

Dr. Robert Cooke, a pediatrician, is president of the Medical College of Pennsylvania. As a director of the Joseph P. Kennedy Foundation, which helps children and parents with special needs, he has had long experience in working with families of special-needs children. The following passage was taken from an interview with Dr. Cooke.

In dealing with special-needs children, I believe the emphasis should be put in terms of the day-to-day life of the individual rather than the long picture ahead:

- What's going to happen tomorrow?
- What's going to happen next week?

I counsel parents of special-needs children not to worry about what's going to happen next year or the year after. Their planning won't accomplish anything. What's the point of worrying whether this child might get to high school when he's only one month old? There are a lot of steps in between, where time and circumstances and community can change and play roles in what may happen to that particular infant. And thinking that a special-needs child may be in an institution 30 years from now, alone, with nobody to take care of it, only yields depression. There's no way a parent can know what the future will mean for their special-needs child.

So parents must consider what they can do for their baby to make things better next week or next month. The emphasis should be on short-range planning.

We overemphasize accomplishment in our children, and worry too much about what they are going to become. Parenting of both normal and abnormal children goes too much in the direction of the end product. Just as the parents of a normal child may push the child to become a lawyer or a doctor, the parents of retarded children stress task accomplishment, but on a different level. I think, in both cases, we should be helping children to develop their individuality and ability to make choices. It becomes especially important to help the retarded child become the best possible person, the most fulfilled person he or she can be, rather than a child who can succeed at tasks.

Young people in the sixties showed that you can be something just playing a guitar on a street corner. I think that's a big lesson, but a hard lesson, because we are so achievement-oriented in this society that we've got the "my son, the doctor" approach to parenting.

Paul Goldberg

19

45

46

CASE STUDY

Geri Gable

"I didn't know that I could bash down some doors, and say, 'Help me, please help me and help this child.' "

Geri, 42, is divorced and the mother of four children. Her second child, Laurie, is 19 and mentally retarded. The diagnosis is brain damage of unknown origin. Geri has had a very difficult life. At the age of six, she was placed in an orphanage. Today she works as a bartender and housecleaner to support her family.

It was not until Laurie was 16 months old that I finally knew that she was mentally retarded. When I finally did get the notification from the one hospital I went into, it was very cold and it made me hysterical. Yet I didn't really know what it was. Well, it was mimeographed, and in the middle I can remember, "Your daughter, Laurie Beth Gable, has brain damage." And that was it. And it was signed by a doctor.

When I first found out that Laurie had brain damage, I thought, well, she's going to be all right, and one morning she'll wake up and, you know, it'll all be gone and everything will be fine.

I was very fortunate because my husband accepted Laurie the way she was. He treated her with a great deal of kindness. But unfortunately, I did not feel that even her grandparents understood what was wrong with her. Her grandparents did not accept Laurie as another grandchild. They felt that Laurie was different. It was not something that they had in their family. It must have come from my family, because they never had mental retardation. They would gladly take their first grandchild, who was no problem. She was the epitome of what a grandchild should be. But Laurie was a problem. And it even got to the point where it was difficult to engage baby sitters. You'd ask someone, "Would you be kind enough to baby-sit? Oh, by the way, I'd like you to know I have a daughter that's mentally retarded." "Oh, I don't know. I . . . I . . . I've never taken care of a little girl like that. I . . . I think I might be frightened to do that."

There was not one social worker, or not one doctor, that said, "You poor kid, you know, here you are, you're 21, you have three kids and you've got one that's mentally retarded. You're married, you know, you've got to cope with everyday living, with the things you wanted, or the things you'd like to do. And you have a husband going out to work, and you're alone seven days a week with this child with no release." You know? "Is there anything we can do to help you?" There was nobody, no one that wanted to take Laurie. They were frightened of her. And so were strangers. So I was a prisoner. They might as well have put me on an island alone with her, and say, "Take care of her." I didn't know that, you know, I could bash down some doors, and say, "Help me, please help me and help this child."

My marriage really wasn't on a solid basis. I never even had time to know my husband. We had three children right away, and one that demanded a great deal of attention. And that is something that is difficult for a young girl to face. And I have seen it wreck marriages.

And one doctor said, "Why don't you put her away?" And I thought that was very cold, because I felt Laurie was my child, she was my responsibility, and there was

John McGannon

something wrong with her. I didn't know exactly what. You know, she was a little bit slow, and she cried a lot, and she was more of a problem than my other child was. But I felt that Laurie was my responsibility and nobody was telling me anything. And I felt that the only thing I could do was to make the best of the situation the way it was.

By chance, I happened to read an article about the way they taught deaf and blind children to see or to understand objects or to talk. She was around two years old. And every day for an hour I would take Laurie's hands and put them on my throat, and I would say one word. And I would graduate from one word to another word, to a sentence. I started out with "Mama," and I graduated to "I love you," and those were the first things she ever said to me was "Mama, I love you."

If you look at Laurie, definitely you can tell that she's menially retarded. She has trouble with her walking, her motor coordination. Sometimes if she gets agitated, she'll start shaking. And she has a cast to an eye. And this was very cute when she was young. You know, it was something that you really didn't notice, because she was pudgy, and brown-eyed, and curly-haired, and cuddly-looking. And she was a love object. Any time you picked her up, she loved to be cuddled. And you could just snuggle down any place with her for hours, you know, and tickle her, and she'd love it.

John McGannon

It never bothered me when she was younger that she wet the bed. Even up until probably she was 15 or 16, she even defecated at night, if she had to, in a diaper. And it didn't bother me. I felt, well, that's one of her disabilities. But a 19-year-old adult wetting her bed has different things. It smells different. The child is older. It's more work. You have to wash the sheets every day, make sure there's a rubber sheet on the bed. You have to make sure that the mattress doesn't smell so the rest of the house doesn't smell. Sometimes Laurie's nose runs now, and it doesn't bother her, but it is very distasteful to other people. You could put up with that when she was ten, and say, "Well, you know, she's ten and maybe she's acting on a five-year-old level." But she's 19.

This past year, it got to a point where she was throwing things, like irons, or taking a baseball bat and trying to bang down a door, having crying spells, almost depressive spells, every single day. I don't mean every other day. I mean every single day. I've tried to talk my daughter out of bad moods. I figure it's a bad situation again. Either I live with it or I just walk away from it. So I try to understand her. I try to talk her out of her moods. I try to do things that won't precipitate a mood. Last year I would have readily accepted Laurie being placed in a home. And I don't really know if I would have cared if it was loving and kind. I really don't know, because I really was at my wit's end.

But the problem subsides, and we get around it, and we get through this week or this day or that month or that holiday. She is much more a part of my life than I can explain to anybody.

CASE STUDY

Bill and Margot Kaldma

"We just felt as though we got a tremendous amount of support from people in the community."

Bill and Margot are in their mid-thirties, and have been married for ten years. Bill is a biochemist who teaches in a university; Margot was a high school teacher before her second child was born. She is now going to school to get a master's degree in public health. Their older daughter, Kristin, is seven; David, their son, is five. He has been blind and slightly retarded since birth.

Bill
I was present at David's birth, and it was a very exciting event. And within an hour and a half of that time, I was informed by our family pediatrician that he had examined David, and that David was totally and permanently blind. And needless to say, it was a pretty stunning blow, because our first child was very healthy, very physically active, very bright.

It just seemed like so much of one's expectations for one's children just kind of disappeared. Then I had to make the decision as to whether and when we should tell Margot about this. And I felt that we should tell her right away, and so we did.

Margot
Your reaction was very protective. When you came into the room, you said that there seemed to be some kind of problem with the eyes. They hadn't quite developed correctly. And I can remember, ringing through that was Bob Goodel's words saying, "Margot, he's going to be totally blind." And he didn't want you to skirt the issue. The implication of what was wrong was the important thing, that we understand that.

My second question, of course, was, "And what else is wrong?" My first hopes were that there were plenty of things wrong, so that David was going to die in the neonatal period, and we wouldn't have to face the consequences of raising a handicapped child. I said, "It would be better if he were dead." And the pediatrician said, "That may or may not be the case, may or may not be true, but in this case, you gave birth to a very healthy child. And he's going to live."

I would say I guess it was a period of four hours in which I made I guess the most important choices as to what was going to happen to this child. The doctor did offer me the out. He said, "I know you nursed your first child. If you don't feel like nursing David. . . ." And at that point I interjected and I said, "Well, if he can't see, he has to be able to feel and hear even more than other children." So at that point I decided I was going to nurse him.

Bill
The day, or within a day of the time that David was born, we called our families to tell them. And it was difficult, because we were in somewhat of an emotional state ourselves. And like all expectant grandparents, they were looking forward to another exciting new grandchild. I remember telling my parents that, that both Margot and David were fine. That they had, that the birth had gone extremely well. But that, I kind of put it almost as an aside, but there was a problem with David that he would not be able to see. And there was sort of a stunned silence at the other end of the telephone, and my parents sort of bravely came back with something like they were sure everything would work out all right. And then subsequent to that, I would say that certainly they gave us a great deal, have given us a great deal of support and their reaction has been, has been very, has been a very positive one.

Karin Rosenthal

Their attitude toward David has been very positive. And that hasn't, I mean I don't think that's certainly hasn't created any real difficulties for us.

Margot
But talking about your family, talking about my family hasn't been exactly the same thing. When I called my parents to tell them, my mother was almost hysterical over the telephone when I called her. And I guess I learned one of the first lessons of raising a handicapped child at that point. I found myself in the awkward position about a day or two after David had been born of having to put somebody else at ease with the situation, rather than looking to somebody else for support. Here I was supporting people around me, and trying to calm them down.

I would say that our relationship with my parents has sort of been up and down. There are things they do which make it obvious that they feel uncomfortable being seen in public with him. I think there's also been some improvement in the situation recently, particularly now that he's talking. My mother's getting a lot more feedback than she did originally, and I think beginning to see that he can be a very cute and engaging child.

Bill
People felt very uncomfortable, even our own friends, about approaching us right after David was born. And we had to make a decision as to how we were going to handle the situation. We could either in effect sort of go into hiding ourselves, or put David into hiding. Or we could just be very open about the whole thing, and very open with David. And we chose the latter.

Everybody knew within a day after David was born, and I went and I talked to people. And people were obviously hesitant to ask, so I just volunteered a few things, without going into long details. And the response to that in the community was just overwhelming. I mean, afterwards we just felt as though we got a tremendous amount of support from people in the community, not only our friends, but just people around town.

David would, we'd go into supermarkets. The produce people and the check-out people all within a matter of a few months knew David, and would say, "Hi," to David. I think that it was very important to go public with David. It was hard on us for the first six months, because people felt so awkward about it. And we had to do a great deal of, well, just deciding what do you tell people when they want to know something, and yet they're sort of afraid to ask. And that's even worse than their not asking.

His development has been slow, but it's been steady. And although he's physically and developmentally behind his age, he's continued to, you know . . . . At one point, we were worried about whether or not he'd ever be able to walk. And David was walking by the time he was three. And then we were concerned, you know, would David ever learn to talk, because his development was so slow. And he's learned to talk.

But as he came to, as he cleared each of these hurdles, it was just, we were I think able to relax a little bit, because some of the things that you are concerned about . . . I mean, there's still plenty to be concerned about, I guess, but some of the major things — would he be able to walk, would he be able to talk, would he be able to function with other people — well, he's doing that now.

Margot
He goes to a special nursery school, and they have a very good program for him, I think. The other children at the nursery school are at his developmental level, but none of them have the same disability. They finger paint and they play with water, and sand. And they sing songs. And do nursery rhymes, and so on. It's been very nice for him. In addition to that, our school system has hired a part-time teacher who is trained to deal with blind children, and she has actually begun working with braille and a stylus with him, and teaching him how to, some of the special mobility skills that blind children need to know. And if he brings his paintings home from school, he has a litle braille name tag on the bottom, and if he goes through papers, and he feels his name tag on it, he just says very proudly, "I made it." Because he knows that he made the things that have the name tag on them.

Bill
Mentioning the fact that David is in a nursery school I think raises another very important thing. I think that from the parents' point of view it is exceedingly important that the parents be relieved of the sense of responsibility that every minute

Karin Rosenthal

of every day that they must be looking after this child and teaching this child. Because a child with a handicap has to be taught many things that normal children just learn by themselves. I mean, David cannot just look around the room and begin to learn and identify objects. You have to bring him to every object or the object to him and have him feel it, learn its name.

Margot
He has to come in contact with the same thing many, many times before he really knows what it is.

Bill
You also, you know, we have come to meet some tremendously fine people through David's handicap, people in the medical profession, people in the social service area, and other people with handicapped children. All people who we would not have met otherwise. I wouldn't advocate people going around and having handicapped children just to have these great experiences, but it is nice to know that there is this other aspect to having a handicapped child, which is very rewarding.

Margot
We found that there are people who can sort of size up the situation, even people with very little education and very little exposure, and seem quite instinctively to know what's the right thing and the good thing to do.

We found that there were high school girls, boys, who really thought it was kind of exciting to learn about a child like David, and to learn how to care for him, and really sought out an experience of that kind. That's one area in which you don't need any kind of special training or expertise, but a certain kind of feeling and a certain kind of willingness can make for assistance and support to the family.

Some of the other kinds of support that people offered without definitely being in the medical or social work profession were friends and neighbors who, for instance, would take care of Kristin while we had a medical appointment with David somewhere else. And then when I came back usually very drained from the whole experience, then they could have a casserole ready and they would just say, "Stop in and have dinner," and particularly give me a chance to talk about what the experience had been very soon after it. That was a very supportive, therapeutic kind of thing that friends did. Maybe they didn't even realize how helpful it really was.

I can also think of the school bus driver that David had last year, who, again, a person without any kind of special expertise, thought in terms of what her own job was — what kinds of things could she do that would make the world more interesting to David, that would promote her interaction with him. Just things like stopping at the railroad track and having to look both ways. She would just wait there for the train to come through and open the door, and say, "David, here comes a train, listen to it choo-choo-choo."

Bill
As I said earlier, I think it's important, in the case of a handicapped child, for parents to have some relief from the constant pressure that they feel of making sure that he learns all the things that he needs to learn. And by that I mean that there is someone else, whether it's a nursery school or some other kind of a place, where he can be for a few hours a day, just to provide some relief. This is of course exceedingly important I think for the mother, because she generally, in our society, does more of the child-rearing than fathers do.

Margot
I see the potential for tremendous divisiveness over a handicapped child. There is a change in the relationship when there are children regardless of whether or not the child is handicapped. It's difficult in your own mind to sort out what are the changes that were forced by having children, what were the changes forced by having a child like David.

Bill
Also, I think that with the longer dependency with a child like David, there are things that you sort of expected to be able to do by a certain time after you've had children and that date is postponed, and so you, that can create problems as well. By the time a kid's five years old, you ought to be able to go off and do certain kinds of things and not have to worry about the details that you have to be constantly worrying about with David. And often that's no more than a petty annoyance, but there's

enough petty annoyances in a marriage and family relationship anyway with four people going off in four different directions, and wanting to do four different things in any given point in time, that it certainly does add an extra difficulty that has to be dealt with.

I think certainly the whole experience of my being at David's birth, and all the way through, has brought us much closer together. We've had with David a set of decisions that had to be made which both of us had to agree on in a way that is different than with a normal child. I mean, those decisions are just easier to make for a normal child. Most normal children will survive even if you make some mistakes in those decisions. It seems less obvious that a severely handicapped child will be able to survive if you make the wrong decisions on some of these things, or to survive it nearly so well. So that I think has certainly had an impact on bringing us closer together, I'd say bringing us closer together as a family.

I think he does clearly realize that he's different in some way. There have been times, though, when he will just repeat a phrase that a child has just asked. Like he'll say, "Where are his eyes? Where are his eyes?" Then he'll say, "He doesn't have any." I know there are times when he's very surprised when we, or someone else, know something that's going on that he doesn't. He often is not sure how we know

that that's happening, because he doesn't know that that's happening. It'll just be a matter of time I suspect and experience that he accumulates that he begins to understand something about really the powers that other people have that he does not have.

Margot
I am quite sure that by the time he is an adult there will be a far wider range between totally independent living on the one hand, and institutionalization on the other hand, in the form of day-care programs, sheltered workshop programs, community-based programs with supervision of people working in the general economy — these kinds of things. And somewhere in that range of services, hopefully, there is a niche that David will be able to fill.

Did You Know?

Range Of Retardation

A person who is mentally retarded is someone whose intelligence, from childhood on, develops more slowly than most people's, and who probably has unusual difficulty learning, getting along with others, and earning a living. Mentally retarded people can and do learn, but there are real limits on how much they can learn. They will not catch up with others of their age who are not retarded.

Children and adults who are mentally retarded are slower in their thinking, but just how much slower they are varies enormously. Mildly retarded children have a hard time in regular school and need special education to help them learn, but they can grow up to hold jobs and live independently. As adults, they don't seem very different from the other people with whom they live and work.

About six percent of the retarded population in this country, or 366,000 persons, are moderately retarded. They need special training to care for themselves and to get along with others. They will always require some supervision and help, from parents, sheltered workshops, and community agencies.

Among the retarded people in this country who are classified as severe (3.5 percent, or 214,000 persons) or profound (1.5 percent, or 92,000 persons), the ability to learn is extremely limited. While some can be trained to handle some basic, personal needs, they will always need someone to take care of them. Many of the profoundly retarded are also handicapped seriously in movement, hearing, vision, or speech, and may have more than one handicap.

Most causes of mental retardation are still unknown. The more than 200 possible causes that we do know about account for only about 25 percent of the cases. What we do know is that mental retardation can be caused by something that happens at the time of fertilization, during pregnancy, at the time of birth, or during infancy or childhood. Much more research is needed before we will understand the factors that can cause a person to be retarded.

Actual damage to the brain can, but does not always, result in mental retardation. Brain damage can also lead to other disorders like cerebral palsy, convulsive seizures, hyperactivity, or trouble in understanding and learning. Some individuals with these problems are retarded; others are not.

Brain damage accounts for many cases of moderate, severe, and profound mental retardation. However, it cannot be shown definitely to be a cause in most cases of mild retardation.

Mental retardation cannot be cured; in only a small number of cases can it be prevented. In *Families and Futures: Helping Self And Others* you will learn how to reduce the risk of mental retardation. But in most cases of retardation, prevention is not yet possible.

We have said that once a person is retarded, there is no cure. However, most mentally retarded people can be helped to lead productive, independent lives. This depends on the seriousness of the retardation, but since nearly all cases of mental retardation are mild, most mentally retarded individuals can and do enjoy fairly normal lifestyles.

Birth Defects: Why Do They Happen?

You've heard the stories of several families who have children with birth defects. As you thought about the lives of these families, you may have wondered about birth defects. What are they? How often do they occur? What causes them? How can they be prevented?

What Is A Serious Birth Defect?

A serious birth defect is something so wrong with the way a baby's body is formed, or the way it functions, that it may kill the baby, or make it very difficult for the child and his or her family to lead a normal life.

Sometimes a defect in an unborn child is so serious that the fetus cannot survive until birth. This happens in perhaps 25 percent of all conceptions. These early deaths are called spontaneous abortions, or miscarriages. A very large proportion of early fetal deaths, about 9 out of 10, result from defects in the unborn child.

Because of birth defects, a child may be mentally retarded or crippled; he or she may require surgery to repair a hole in the heart, or have a disease, like cystic fibrosis, that needs constant medical care. A few of these serious birth defects can be cured. Many can be improved by medical treatment, or other kinds of special help. And some are fatal.

How Many Babies Are Born With Birth Defects?

Of the 3.3 million babies born in the United States in 1977, more than 250,000 (or one out of 14) had birth defects.

How Do You Know If A Child Has A Birth Defect?

Some defects can be diagnosed by a doctor soon after birth — for example, Down's Syndrome, which is one major cause of mental retardation; or a valve in the heart that doesn't open and close the way it should; or a cleft palate. Other defects are things that parents are likely to notice first, because their baby doesn't seem to be doing the things that other babies are doing at the same age. Defects like cerebral palsy, some kinds of deafness, and brain damage are some of the problems parents are apt to detect. Some defects, like cystic fibrosis or Tay-Sachs disease, don't show up until a child is six or seven months old. Some, like diabetes and Huntington's disease, may not be apparent until the age of 45 or 50.

What Is Known About The Causes Of Birth Defects?

Doctors do not always know the cause. By one researcher's estimate,* the known and unknown causes of birth defects break down this way:

Known Agent	*Percentage of defects thought to be caused*
Genetic defect	*20 percent*
Chromosomal accident	*5 percent*
Environmental	
• *Radiation for diagnosis and treatment of illness*	*1 percent*
• *Infections*	*2-3 percent*
• *Maternal metabolic problems like thyroid malfunction and diabetes*	*2 percent*
Unknown	*65-70 percent*

* Table adapted from J.F. Wilson, "Environmental Effects on Development-Teratology," in *Pathophysiology of Gestation,* Vol. 2, pp. 269-320. New York: Academic Press, 1972.

Knowledge in this field keeps accumulating as research into the causes of birth defects continues. For example, 20 years ago no one could have explained to Jenny MacLean how Down's Syndrome happened. Now Down's Syndrome is well understood. It can even be diagnosed before a baby is born, although it cannot be prevented. However, the kind of brain damage that Geri's daughter Laurie suffers from could have resulted from a variety of causes; no one knows why this happened to Laurie.

Why Are Some Babies Born With Defects?

To understand why some children are born with defects, you need to know something about the factors that determine the condition of all newborn babies. What a baby is like at birth is determined by two kinds of factors.

- The particular mixture of characteristics inherited from the parents at the moment of conception. These characteristics come not only from the parents, but from the parents' family histories, back through many generations.
- The way these inherited characteristics are influenced by things that happen in the nine months between conception and birth.

The first group of factors is usually called *heredity;* the second is called *prenatal environment.* Inherited characteristics are often affected by the prenatal environment. Thus, by the time a baby is born, it's very difficult to analyze which qualities are caused by heredity, and which by environment.

John McGannon

Inheritance: The Biological Connection

Unique...

Each baby is born unique. Each one is a new person, different from all the other babies who have ever been born or ever will be. Newborn babies don't really look alike — even though people who haven't been around them much may think so. Some babies are born with lots of hair on their heads; others have no hair at all. Some babies are long and some are short. Some are fat and some are thin. Some seem pretty to grownups, while others may look funny.

Newborn babies don't all act the same way. When and how much they sleep or stay awake differs widely. Some cry a lot and others don't. The way babies' cries sound also differs. Different babies need to be comforted in different ways, too.

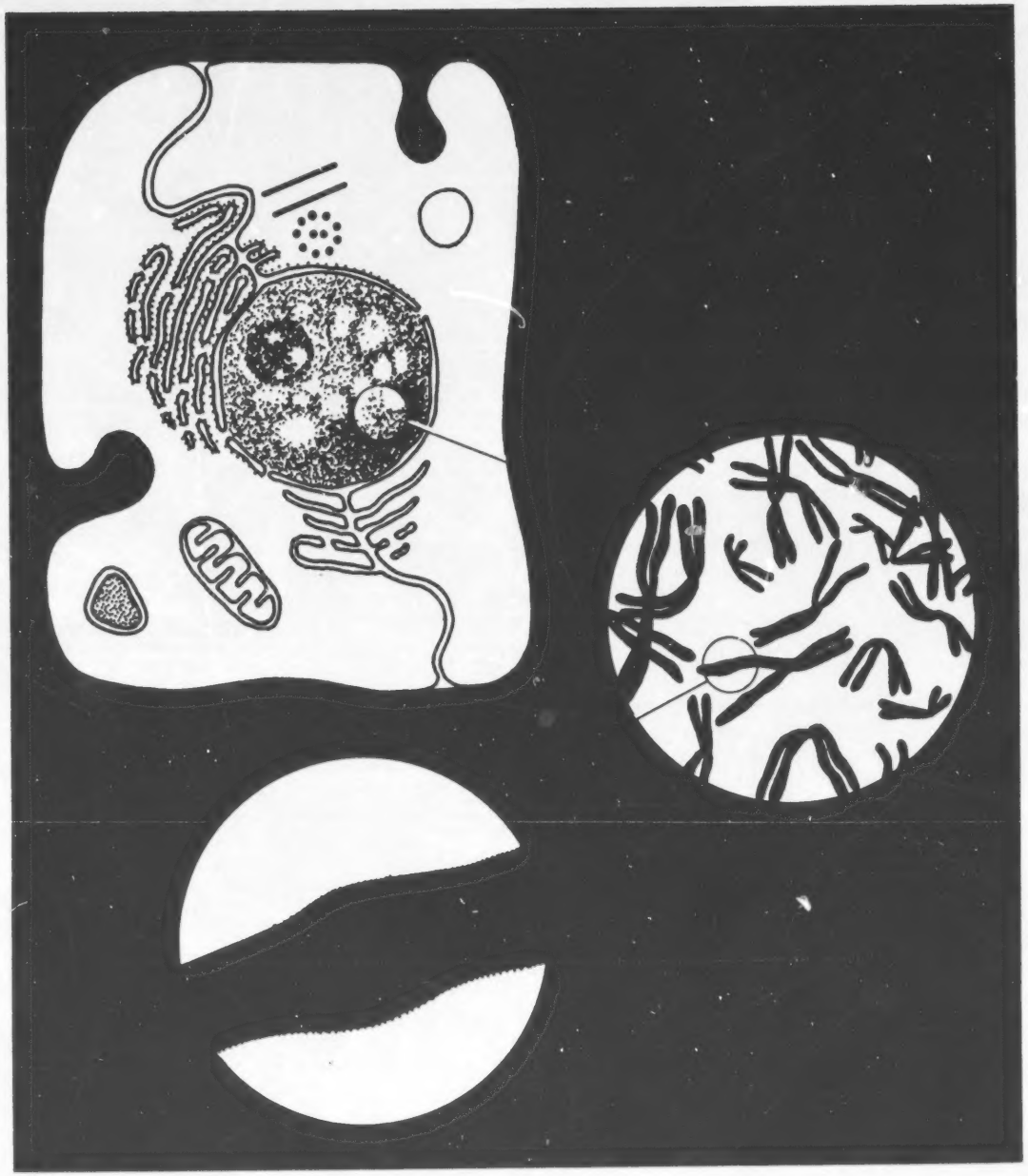
...Yet Connected

Each new baby is connected to other people, to the past and to the future. Babies are connected to the past through their parents and grandparents, back through the generations. They are connected to the future through their own children and grandchildren. The biological thread that connects human beings to each other in the past and the future is called inheritance.

How Does Inheritance Work?

What makes some family members look alike? What makes each person in a family slightly or even greatly different from the others? What is it that makes all human beings similar, and yet makes each one unique?

To explore these questions, we have to look at what makes us human beings. Why do male and female human beings produce other human beings and not dogs or cats? The question sounds silly, but answering it will help us understand what human beings are and how they get that way.



DNA

The actual material of inheritance, the stuff that directs the development of each individual, is very similar for dogs, cats, and human beings — in fact, for all species.

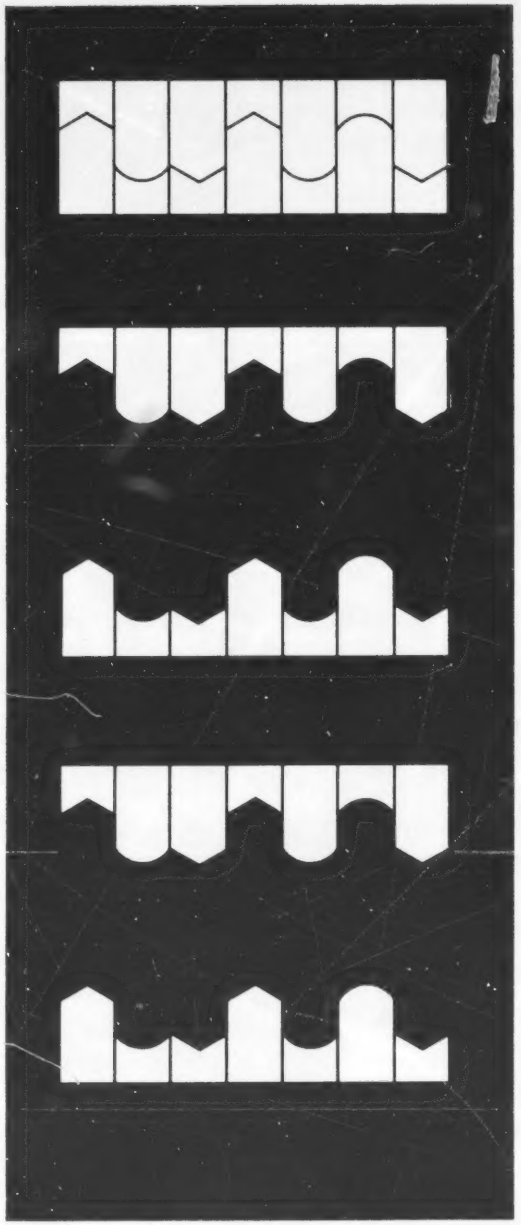
This hereditary material is an acid called DNA. DNA is a marvelous material.

- It supplies the coded information that every cell in the body needs to reproduce itself.
- It copies this coded information accurately every time it reproduces itself.
- It allows all kinds of creatures (organisms) to reproduce more organisms like themselves.
- It can exist in many different forms that carry the many different kinds of coded information needed for the millions of plants and animal species in the world.

DNA is composed of five simple elements — carbon, hydrogen, oxygen, nitrogen, and phosphorous. All DNA is made of these elements, whether it is DNA in human beings, dogs, cats, or horses. This similar make-up of DNA makes it difficult to understand how there can be so much variety in living organisms — from one species to another, and even within our own human species. The reason is found in the structure of DNA, which is composed of four different chemical units. Each unit contains the five elements above, although in different arrangements.

DNA structure can be compared roughly to a ladder in which any rung could be painted in one of four colors. Even for ladders of ten rungs, there would be many different kinds of ladders that could be built, each having a different sequence of colored rungs. A DNA "ladder," however, consists of thousands or millions of rungs and the number of different kinds of ladders that could be built would be practically infinite.

Another comparison is to look at the four different chemical units of DNA as four letters of an alphabet. The 26 letters of our alphabet are strung together in different ways on this page to create many different words and messages. In the same way, the four letters of the DNA alphabet are strung together in different ways to create the many different messages needed for development of humans versus dogs or cats.



The many differences in their DNA cause human beings to reproduce human beings and dogs to reproduce dogs. Similarities among family members are passed from one generation to another by DNA. Sometimes these similarities skip a generation or more and then reappear. But the DNA coding for the similarities did not skip generations. For example, if both parents have brown hair, it is still possible to have a child with red hair, just like a grandparent or earlier ancestor. As explained later, it is possible for a brown-haired person to carry and transmit the DNA code for red hair as well as the DNA code for brown hair.

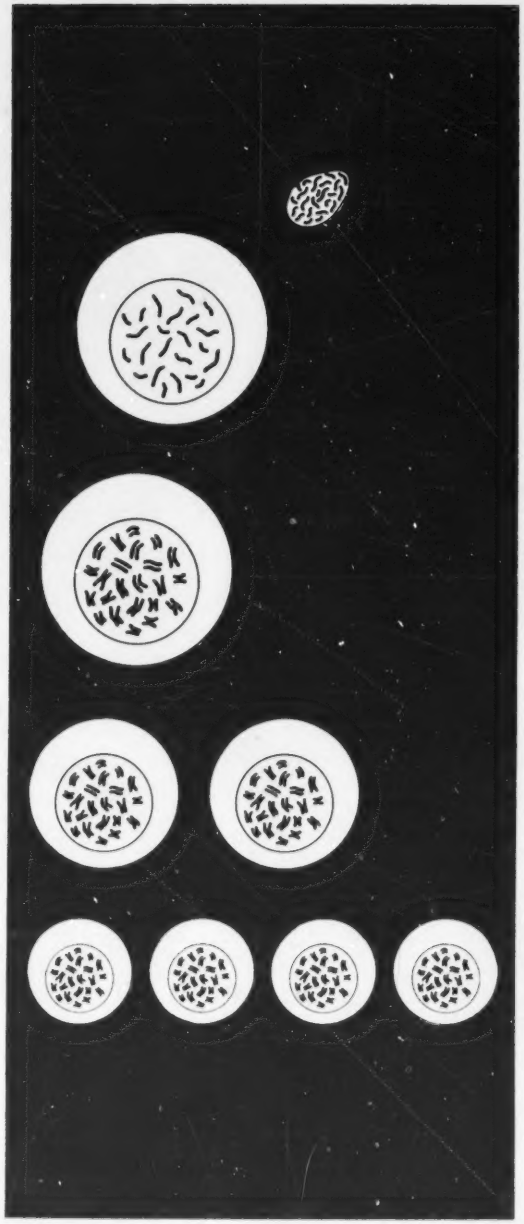
Fertilization

Each of us is the result of the information that was transmitted by DNA at the precise moment that the sperm from our father fertilized the egg cell of our mother.

The fertilized egg is called a zygote. This one cell, following instructions from DNA, reproduces itself time after time, until it finally produces a fairly developed human being with cells of many different shapes and functions. A human being is made up of billions of cells, each of which contains the DNA code.

Some months after a girl has her first menstrual period — which usually happens between the ages of 9 and 16 — she will begin to ovulate. This means that about midway between one period and the next, a tiny egg is released from one of the ovaries where the eggs are produced. The egg moves down into the birth canal. If a girl has sexual intercourse during those days when the egg is traveling from the ovary to the vagina, she is likely to become pregnant.

This pattern of ovulation is repeated for most females about every 28 to 30 days. But the timing of ovulation can vary from one month to another, especially in young girls. It is hard to predict exactly which days of the month a girl or woman can become pregnant.



Genes And Chromosomes

The DNA inside each cell is present in threadlike bodies called chromosomes. In humans the egg cell and sperm cell each have 23 chromosomes, the number necessary in our species to carry the complete DNA code. The chromosomes are different lengths and contain different amounts and kinds of DNA. The fertilized egg, or zygote, formed by the fusion of the sperm and egg cell now has 23 matched pairs of chromosomes, or 46 chromosomes altogether. Thus each person inherits two complete DNA codes, one from each parent.

Each time the zygote divides, the chromosomes make copies of themselves for each new cell. As the zygote develops into the billions of cells needed to make a human being, each new cell contains 23 *pairs* of chromosomes. Only when the sperm or egg cells are formed is the number of chromosomes reduced to 23 again. All other cells in the body contain 46 chromosomes.

The DNA in the chromosomes consists of smaller units called genes. The genes are arranged in lines on the 23 kinds of chromosomes. There are thousands of genes lined up on each chromosome. Each gene carries the code for one piece of information. Every cell in the body is the way it is because of the messages brought to it by the genes. The message may be to make a protein, or a part of a protein, or something else needed for the growth or functioning of the body.

Information stored in the genes directs one cell to become bone tissue and another to form part of the lens of the eye. Genetic information makes the blood of a particular baby Type AB, and shapes the lens of the right eye in another baby so that the child will be nearsighted and need glasses one day. It determines that one baby will grow up to be tall and lean, but that her brother will have a stocky build and a tendency to be overweight.

Genes work actively at different times to develop the human being. They cause the zygote to become a fetus and then develop into a baby. After the baby is born, the genes continue to work. They help build the baby into a child and then into an adult.

How Genes Work

Each gene has its own position on one of the chromosomes. For each gene from the mother, there is a partner gene in the same position on the matching chromosomes from the father.

The characteristics or traits you see in your own body are the result of the way in which your genes interact. If the coded information in one gene — for example, red hair — is the same as the information in its partner, then both genes called for red hair and red hair developed. Likewise, if both genes had coded information for brown hair, then brown hair developed. But one gene may code for brown hair while its partner codes for red hair. What happens then? Each characteristic or trait has to be studied separately to answer this question. In this case brown hair develops. The gene for red hair, although present, is not expressed. This does not affect its chances of being transmitted to your children. Your children could inherit either gene.

The terms used to describe this kind of gene interaction are dominant and recessive. The gene for red hair is called recessive because it is not expressed when a gene for brown hair is also present. The brown hair gene is called dominant. These terms are also used for the differences in the trait controlled by the gene pair. Thus red hair is recessive to brown hair. Saying brown hair is dominant to red hair means exactly the same thing. Genes coding for recessive traits must be present in both members of a gene pair in order for the trait to show. But genes coding for dominant traits can be present in both members of a gene pair, or in only one member in order for the trait to show.

Many other (but not all) genes interact in a similar way. Look at your hairline. If your hairlines dips down to a point in the center of your forehead, you have a widow's peak, a dominant trait. You may have inherited the gene that codes for this characteristic from either one of your parents. The matching gene from the other parent may not have had that piece of information. It may have coded for a straight hairline. For dominant traits it is possible to inherit the trait from only one parent.

Let's take another trait. Take a look at your earlobes in a mirror. Most people's earlobes are fleshy and hang down (pendant earlobes). But some people do not have pendant earlobes. They have little or no flesh below the earlobe. We say they have attached earlobes. This is recessive to pendant earlobes. To have attached earlobes, a person would have to receive a gene that codes for attached earlobes from both parents. There would be no gene from either parent for pendant earlobes.

What is puzzling is that both parents of this child may have pendant earlobes! In such a case, each parent must have inherited one gene for attached earlobes and one gene for pendant earlobes. They were both carriers of the recessive gene for attached earlobes and both happened to transmit the recessive gene, rather than the dominant one, to the child.

Some traits are also sex-linked. The genes controlling such traits are located on the same chromosome that has a sex-determining function. One result is that sex-linked traits like color blindness occur with a different frequency in males and females. Hemophilia, a recessive trait that causes frequent and easy bleeding, is sex-linked. If a normal woman who is a carrier of the recessive gene marries a normal man, only the male children have the risk of being affected by hemophilia.

Do Genes Tell The Whole Story?

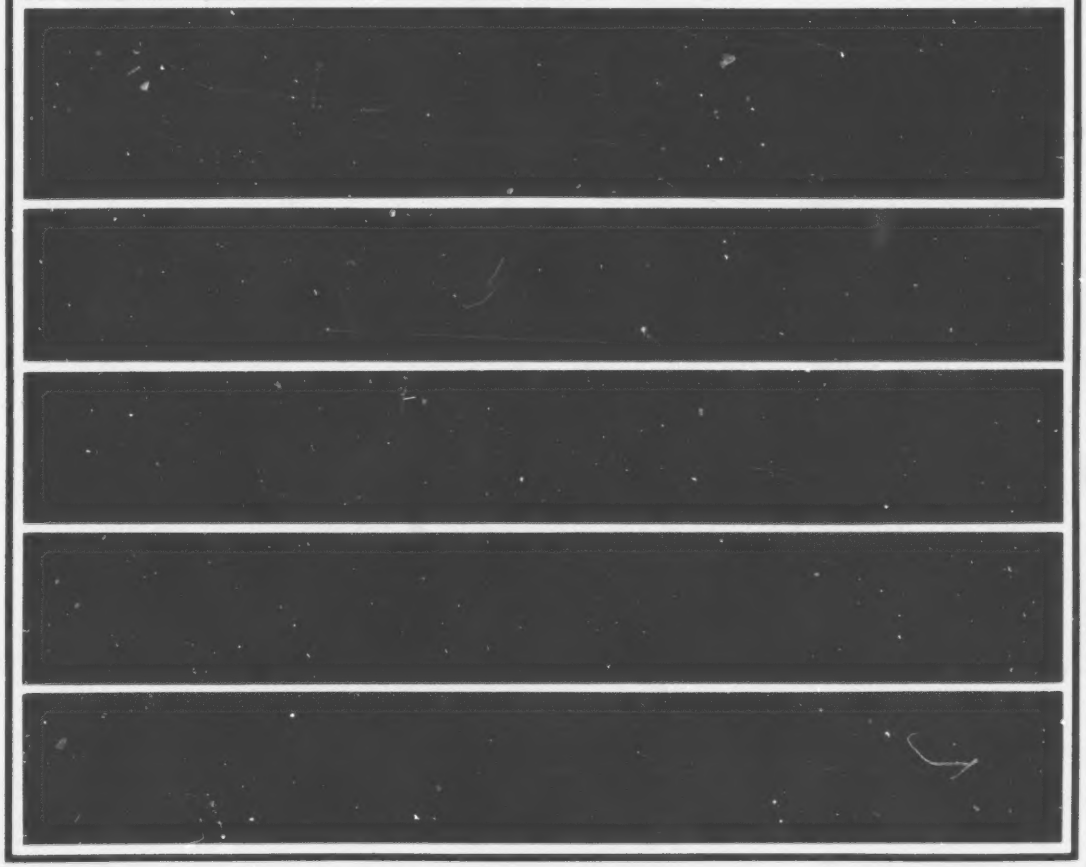
The combination of genes that a baby receives from the mother and father determines what that baby can become physically. Such traits as eye and hair color are not affected by the environment. But for many important traits such as intelligence, personality, or body build the genes give the baby a potential development. What actually happens to that potential depends on the environment in which the baby grows before and after birth.

Suppose a fertilized egg is carrying genes from both parents for the development of a person who is taller than average and who has broad shoulders and strong muscles. Many genes would be needed to transmit all this information. But let's suppose the mother of this child does not get enough to eat, or enough of the right kind of food, while she is pregnant. Let's also suppose the baby is poorly nourished after birth. The environment will hold back the potential that the child's genes allow. He or she will probably not be as tall, as strong, or as well-built as he or she could have been.

82

Did You Know?

It may be difficult to think of life being made up of such unimagineably small pieces of material but it is these pieces of information that make the wonder of life so awesome.



83

Inheritance And Birth Defects

A baby is the product of the genetic inheritance of both mother and father. And, as mentioned earlier, a baby is also the product of the care it received during pregnancy. If something goes wrong, either with the genetic inheritance of the baby or with its development in the uterus, the baby may be born with a birth defect.

Birth defects may be slight or severe — something as mild and correctable as nearsightedness, or something as difficult and ongoing as cerebral palsy or severe mental retardation.

There are three types of errors that can lead to birth defects:

- *Genetic errors,* in which the genes of one or both parents carry a defect that is passed on to the baby.
- *Chromosomal errors,* in which both parents may have normal genes in their own cells, but in the process of producing egg or sperm (or in the union of egg and sperm) the chromosomes for the new infant become damaged or broken.
- *Environmental errors,* in which the genetic makeup of the fetus is normal but factors during its development in the uterus harm it.

These different kinds of errors tell us something about the cause of a defect, but they do not predict the severity of the problem or the type of remediation necessary.

Inherited Birth Defects: Genetic Errors

Some birth defects can be passed on to a child from the mother, the father, or from both parents. Examples include hemophilia, muscular dystrophy, and some forms of mental retardation.

The defect may come from the parents' genes. There are tens of thousands of genes in each egg and each sperm, and almost all of them carry the correct instructions for normal development. A few genes may carry a wrong instruction, an error.

Because most defective genes are recessive, a person can carry the gene for a birth defect without actually having it. If only one parent is a carrier, there is no chance that the children will have that defect (although they could also be carriers). If both parents are carriers for the same defect, there is a risk each time they have a child that it will be born with that defect.

There are doctors and other specialists who diagnose birth defects, treat the children who have them, and help parents to cope with the problems. Such specialists are called genetic counselors. Genetic counselors advise parents about the risk of having children with birth defects. Not all hospitals provide this service, but if you think you need it, and you can look around for it, you can usually find resources that can help.

For some birth defects, a genetic counselor can tell parents if they are carriers. The doctor cannot predict for sure that a particular child will have the defect, but he or she can give the parents the odds.

For birth defects that are recessive and carried by both parents — and neither parent has the defect — the odds are one in four that the children will have the defect. The odds that a child will not have the defect but will be a carrier are 50/50. And the odds that a child will neither have the defect nor carry the gene are one in four. Some recessive birth defects are:

- cystic fibrosis
- Tay-Sachs disease
- sickle cell anemia
- phenylketonuria

Some defective genes are dominant, which means that anyone who carries the gene has the defect. If either parent has a dominant defective gene, the odds are 50/50 each time they have a child that it will be born with the defect. Some dominant birth defects are:

- extra fingers or toes
- Huntington's disease

Chromosomal Errors

Some birth defects are not caused by wrongly coded genes that parents carry, but by an error in the number of chromosomes. Most human beings have 46 chromosomes in every cell. Sometimes, when egg and sperm are being formed, or when a sperm and egg unite at fertilization, there is an accident. Instead of a normal fertilized egg with 23 pairs of chromosomes, the zygote receives an extra chromosome or is missing one chromosome of a pair.

If a fertilized egg has the wrong number of chromosomes, the coding information in the genes will not be carried out properly. The result is usually a birth defect — or a group of defects — in the child. Some chromosomal birth defects are:

- Down's Syndrome
- Turner's Syndrome
- Klinefelter's Syndrome

Chromosomal errors are often one time accidents, not the result of a defective gene or chromosome in either parent. But there are some situations when they are more likely to occur and it is worth trying to discover if the unborn fetus has the chromosomal error. For example, Down's Syndrome occurs most often among children of older mothers (over 35 years of age). Doctors can test for the chromosomal error by taking a sample of the amniotic fluid in the mother's womb. This procedure is called amniocentesis. By looking at cells from the baby that flake off into the fluid, scientists can count the number of chromosomes the baby has, and tell the parents whether the unborn child has a chromosomal defect.

Other Defects

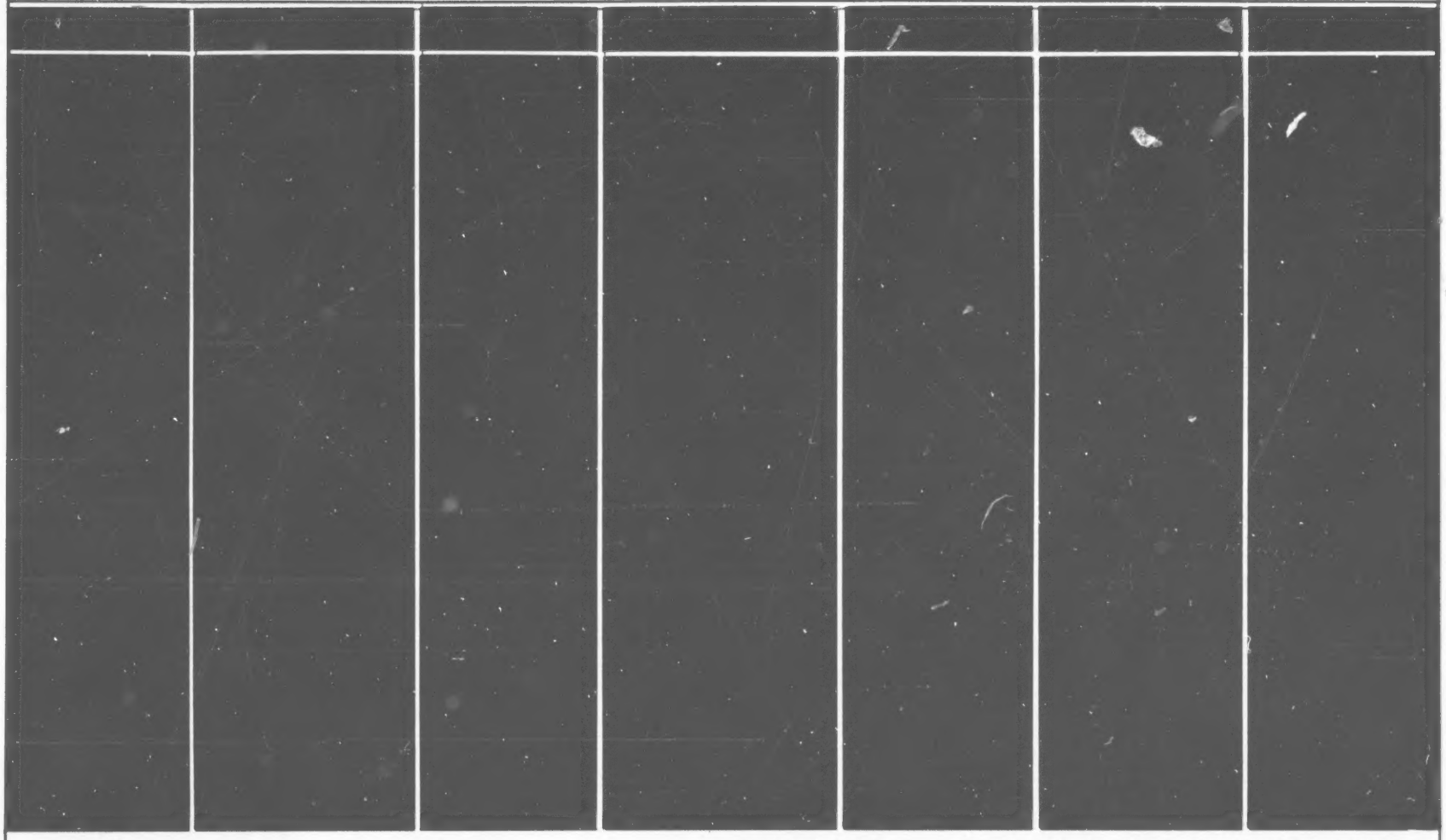
Birth defects are not always inherited. Many occur after conception, while the baby is developing as a fetus. From conception until birth, an unborn baby lives and grows in the environment of the mother's womb. Factors in that environment can damage the fetus. Among these are the mother's diet, an attack of rubella (German measles) in early pregnancy, or drug use while pregnant.

In fact, most birth defects are caused by a combination of heredity and environment. Heredity may make an unborn baby weaker in some way, and more easily hurt by a problem in the mother's diet, a pill whose long-term or side effects are not known, or an infection she develops. Sometimes a woman who has a disease like rubella during pregnancy will give birth to a perfectly healthy child. But another woman, whose child is genetically different, may catch rubella and her baby will be born deaf.

Some birth defects caused by a combination of heredity and environment are:

- heart malformation
- spina bifida
- club foot
- cleft palate and/or harelip
- diabetes

Some Common Birth Defects



*Incidence: the number of new cases diagnosed during a year.

**Last three columns list possible means now known for detection, treatment, and prevention. The techniques may not necessarily be applicable or successful in every case.

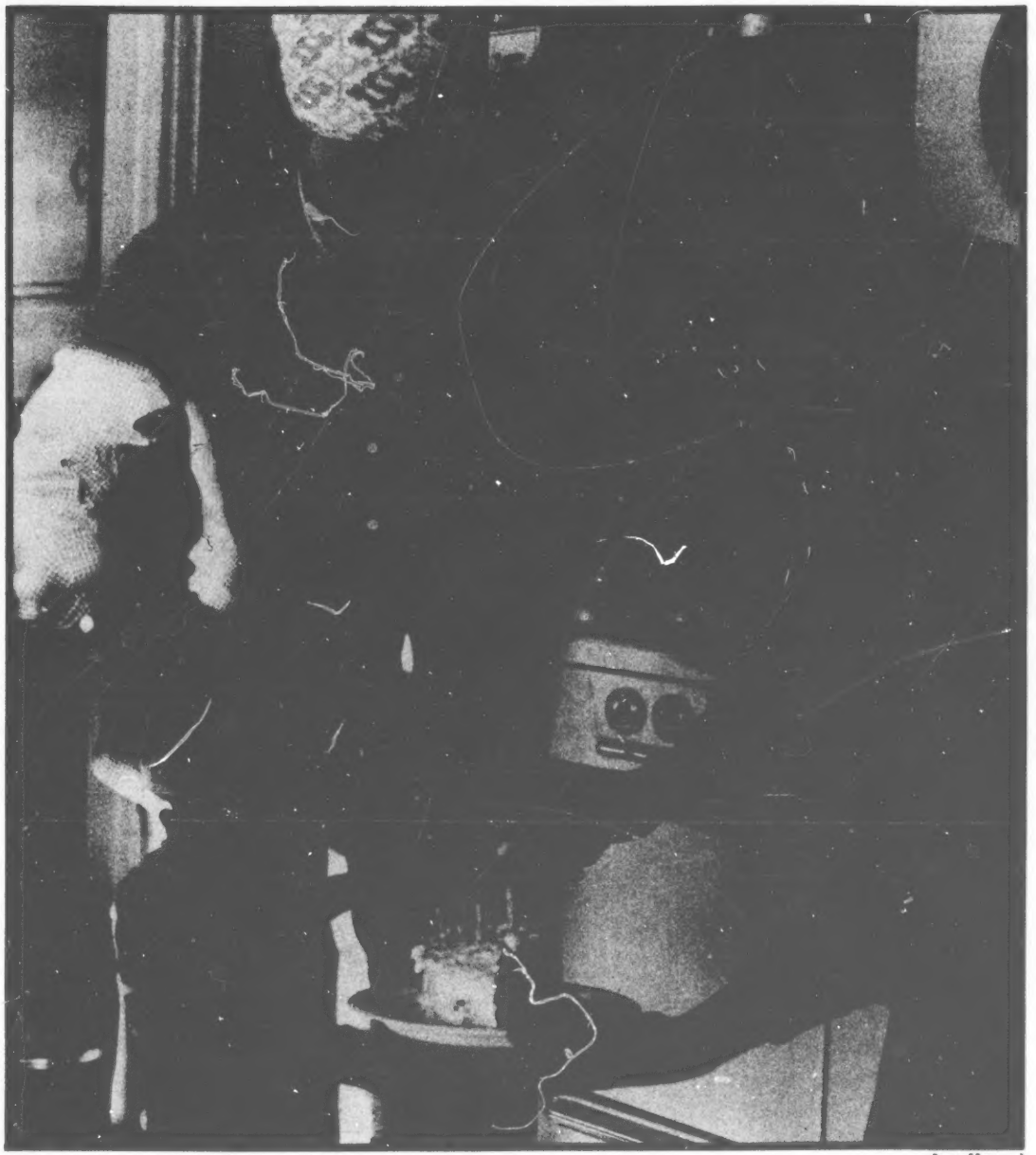
+Weighing 4 lbs. 6 oz. or less.

From Birth Defects: The Tragedy and the Hope, The National Foundation/March of Dimes, White Plains, New York, 1977. The Foundation estimates that among Americans of all ages, birth defects afflict: 4 million with diabetes; 580,000 born completely or partially blind; 300,000 with congenital hearing impairments; 350,000 with heart or circulatory defects; 170,000 with severe speech problems; millions of others with defects of the nervous, digestive, endocrine, urinary, and other body systems.

88

89

Parents And Their Children's Health



Jerry Howard

Biologically speaking, human beings are a successful species. Most of them survive, grow up, and reproduce. Human beings have a tendency to develop in a healthy manner, but problems can arise.

Parents play a major role in their children's health. They affect the health of their children in two ways:

- Through the inherited characteristics they pass on to their children.
- Through the quality of the environment in which their children live and grow, before and after birth.

People often comment on the inherited features of healthy newborn babies: "She has her father's rosy cheeks." "That clear skin is just like his grandmother's." Later on, many of the good effects of the environment on children's health are also obvious. But some effects of inheritance and environment are not as obvious and some are quite harmful.

It is important to know how much of a child's future may be determined by the characteristics of the infant at birth, and how much may be shaped by the course of life after birth. From the moment a baby is conceived, he or she interacts with the world. Human growth and development involve a series of exchanges between the biological qualities of a child and the environment in which the child grows.

Many children are born who are less than perfectly healthy. Their mothers may have had a difficult pregnancy. The baby may weigh less than five pounds at birth. The newborn baby may cry constantly or be extremely restless, hard to feed, and hard to comfort. If babies like these are cared for well, if they are fed well and cuddled, played with and loved, the basic human tendency toward health tends to win out. Most babies with early problems grow into healthy adults if they have good care.

Glossary

A glossary defines words you may not know that are important to understand. Reading straight through it may give you some new information about birth defects and other subjects important to the health of parents, children, and teenagers.

Addict A person who must have a substance, usually harmful, for daily life. Addiction usually means there is a physical dependency (need), as in alcohol, heroin, etc. There are also psychological or emotional addictions, in which the substance is used as a crutch but is not physically addictive. Ending the use of an addictive substance will cause craving (strong desire similar to hunger or thirst) and other withdrawal symptoms such as pains, aches, nausea, vomiting, cramps.

People may use a substance, like alcohol or heroin, and not be addicts. Heavy use of a substance is often as serious as addiction, however. When a pregnant mother is addicted to a substance like heroin, the baby may be born an addict and go through withdrawal. Heavy use of both heroin and alcohol can cause serious birth defects.

Alcoholism Addiction to alcohol. Help is available through groups like Alcoholics Anonymous, ALANON, and ALATEEN, and is absolutely necessary for pregnant women who drink a lot or are alcoholics.

Anesthesia Loss of sensation that may be caused by certain drugs called anesthetics that are usually given before an operation or sometimes during a difficult birth.

Brain Damage Injury to the brain may occur during pregnancy, at birth, during infancy, or later, sometimes resulting in retardation, disorders of the nervous system, such as cerebral palsy and epilepsy, or physical disabilities.

Cartilage White, semi-opaque tissue found in all human beings. Also called gristle. In infants, most cartilage begins to form into bone, a process that continues for many years of growth.

Cerebral Palsy (CP) Disorder of the nervous system characterized by disturbances of motor function. This means the person has difficulty controlling his/her movements. Cerebral palsy usually occurs at birth, but damage or injury to the brain that occurs at any time in life can cause the disability. Commonly, a person with CP may have difficulties with balance, speech, spasms, and limb movement. Some people need crutches or wheelchairs while others can walk and move about independently. Intelligence ranges from above-average to severely retarded.

Chromosome The threadlike material in humans and other animals that carries the genes into the core or nucleus of cells in order to pass on inherited traits or characteristics from the parents to the children. Chromosomes can be seen only under a powerful microscope. There are 23 pairs of chromosomes in each fertilized egg. Every time a new cell is produced, the chromosomes make copies of themselves.

Cleft Palate and Cleft Lip A birth defect that keeps two sides of the lip or the palate (roof of the mouth) from joining together. About 4,300 children are born each year with this problem, which can usually be corrected by surgery. It can be inherited and/or caused by conditions during pregnancy or at birth.

Club Foot A foot that is deformed before or at birth. Like cleft palate and cleft lip it can be inherited and/or caused by influences during pregnancy or at birth. This deformity and others like it can be corrected. Unfortunately many families do not know this, or cannot pay for the surgery, or are afraid or unwilling to have the operation performed.

Colic Many healthy babies get this condition during the first few months. Symptoms include constant crying, gas, and stomach pains. It goes away as the baby grows. It may be caused by rapid growth or by the sudden change from the womb to the outside world. Colic is seldom serious, but it takes much time and energy from the parents.

Conception The sperm from the man fertilizes the woman's egg during intercourse.

Convulsion Sudden jerking or spasms (involuntary muscle contractions) with possible loss of consciousness (fainting) and temporary halt to breathing. Convulsions may be a sign of brain damage in infants. Convulsions also happen with very high fever. They may or may not be serious.

Cystic Fibrosis This disease, which is inherited, affects the mucus glands. It causes a thick fluid to develop in the lungs and intestines, making it difficult to breathe or digest food. About one out of every 2,000 babies has it—it is one of the most common inherited diseases among Northern Europeans. Those who have it may live into their twenties, with medical help. There is no known cure.

Depression A feeling of being down, unhappy, lacking energy, angry at self, apathetic toward self and others. Extreme and lasting depression becomes an illness that is often unrecognized and untreated, although there have been recent developments in treatment through vitamins and diet as well as drugs. Little is known about the many different forms of depression; some may be caused physically or may be inherited, while others may be caused by problems in life or work. Almost everyone suffers short, mild depression. Depression may occur at certain points in life, such as menopause in women, and right after giving birth (which is called postpartum depression).

DES A medicine that was once prescribed to help women avoid miscarriages or spontaneous abortions, and as a "morning after" birth control pill. Daughters born to women treated with DES may get cancer and sons may become sterile. It is also used to fatten cattle.

Developmental Disabilities Children with developmental disabilities are children with mental retardation, cerebral palsy, epilepsy, or combinations of these or related disabilities.

Diabetes An inherited disease affecting the body's ability to break down and convert sugar and starches to energy to be used by the cells. Diabetes may become evident in childhood, but more often symptoms appear in middle age. Usually diabetes can be controlled by medicine and diet. Diabetic women under good supervision can have healthy babies. Symptoms include craving sweets, sweating, cold or itching hands and feet, problems with seeing and/or urinating, nervousness, extreme tiredness. Although it is easy to control and very common, diabetes is a good example of an inherited disease that causes real problems for those who have it and their families. There are daily shots or medicines, special foods to be eaten or avoided, and instructions for emergencies when medicine is not taken or too much or too little sugar is consumed. Diabetics must use artificial sweeteners. Many are fighting the proposed ban on saccharin, which is said to be a possible cause of cancer, because life without it would be even more complicated. Researchers are working on developing other artificial sweeteners to replace saccharin.

Dominant Trait A characteristic that will pass on to the children if either parent has that gene.

Down's Syndrome A chromosomal disorder resulting in extra chromosome material that causes an irregular structure of genes. This disorder is characterized by facial and physical abnormalities such as slanting eyes that are far apart, small ears, a flattened nose, and shorter than average hands, feet, neck, torso, arms, and legs. Individuals with Down's Syndrome are mentally retarded, the degree of retardation usually ranging from moderate to severe. This disorder is more likely to occur in children born to mothers who are over 35 or under 17.

DNA An organic acid in all species of creatures that causes inheritance by creating and reproducing genes and chromosomes.

Edema A swelling that happens when fluid is collected in body tissues. In a pregnant woman, it is a symptom of a very serious condition called toxemia.

Embryo The word for an unborn child from a time shortly after conception to about the end of the third month.

Environment The setting or conditions in which something exists; the world in which we live. The environment of pregnancy, for instance, includes the lifestyle of the mother, her nutrition and general health, as well as the products and emotions to which she is exposed and the social and economic conditions of her family and community. It is often contrasted with heredity.

Epilepsy A disorder of the control of impulses of the central nervous system, characterized by convulsive seizures, loss of consciousness, and disturbance of the sensory and motor systems. Epilepsy may (but does not always) accompany brain damage, and sometimes it is complicated by retardation. It is treatable with anti-convulsant drugs.

Fallopian Tubes (oviducts) A pair of slender tubes in the female that form canals from the ovaries to the uterus. The egg, when released from the ovary, passes into one of these tubes; if sperm are present, fertilization usually occurs here. Otherwise the egg passes through the uterus to the vagina and out of the body.

Fetus The unborn child from the end of the third month of pregnancy until birth.

Gargoylism A congenital abnormality characterized chiefly by grotesque deformities of the head, trunk, and limbs, dwarfism, mental retardation, and enlargement of the liver and spleen. Deafness, joint contractures, and cardiovascular defects are also characteristic of gargoylism. A recessive trait, it is also known as "Hurler's Syndrome."

Gene A small particle (made of carbon, hydrogen, oxygen, nitrogen, and phosphorous) that contains one trait or characteristic from a parent. The genes are arranged in various ways along the 23 chromosomes. A gene may carry the message to make a protein, to make skin, etc. This information directs the cells to become various parts of the body. How they are arranged in the chromosomes determines whether we have brown or blue eyes, freckles, birth defects, tongues that curl, and all our other physical traits.

German Measles See Rubella.

Gonorrhea See Venereal Disease.

Gynecologist A doctor who specializes in the female reproductive system.

Hemophilia An hereditary disease caused by a recessive trait passed from the mother usually only to sons. It is characterized by an extremely slow rate of clotting and can result in severe bleeding from the smallest scratches. Although it is painful and dangerous, it can be controlled by injection and transfusion. The occurrence of hemophilia in a number of royal families in Europe, including the Romanoffs and the Bourbons, has been traced back to Queen Victoria of England as the primary source of this gene among royalty.

Heredity (Inheritance) The physical and other traits or characteristics that are passed from parents to their children. They may be modified by environment. It is important to remember that most defects and diseases, as well as other traits, are caused by a combination of heredity and environment.

Herpes Simplex See Venereal Disease.

Huntington's Disease An inherited disease caused by a dominant trait. The symptoms usually do not show up until age 30 or older. It causes the brain and nervous system to deteriorate slowly, and affects movement and speech. It is sometimes mistaken for drunkenness. The musician Woodie Guthrie died of it, as the movie *Bound for Glory* showed.

Hyperactivity A term used to describe several conditions and symptoms, especially in children. Hyperactive children are jittery and constantly moving. There is some evidence that hyperactivity may be caused by lead poisoning and by some of the preservatives and other substances in various "junk" foods. Some doctors claim to have reduced or eliminated it through diet. Other hyperactive children are treated with drugs. Some people argue that hyperactivity in children should be acceptable, and that the primary problem is the negative attitude of adults toward children with this characteristic.

Incubator An artificial environment prepared for premature babies to help them survive. An incubator imitates some of the conditions of the womb.

Infantile Autism A developmental disturbance reflecting the inability to relate appropriately to self, objects, and people. Functional retardation occurs, with many accompanying disturbances of behavior and communication.

Low Birth Weight Average birth weight is about seven pounds, five ounces. Less than five pounds is considered low birth weight. Many babies, but not all, who weigh less than 5.5 pounds are premature—born sooner than nine months. Low-weight babies have high risks. The risk of death is 17 times higher than for full-weight babies. They suffer more often from CP, epilepsy, mental retardation, deafness, blindness, deformities, and other problems. Low birth weight is often associated with poverty, poor nutrition, and poor prenatal care.

Mainstreaming A word used in some states to indicate that special-needs children are educated in classes with normal children.

Malignant Cancerous. A tumor or substance that is malignant contains and/or causes cancer.

Malnutrition Lack of the right foods to the point that the person is harmed physically or emotionally. Malnutrition may cause temporary or permanent brain damage and other problems in the unborn, infants, children, and adults. It is usually, but not always, associated with poverty.

Maternal Having to do with the mother. Maternity has to do with a pregnant woman: maternity clothes, maternity death rate, etc.

Menopause The time, usually between the ages of 45 and 55, when women stop menstruating.

Menstruation The discharge of blood and mucus from the uterus that usually occurs in sexually mature females in cycles of about a month each. Menstrual means anything connected with menstruation.

Mental Retardation Mental retardation covers a wide variety of disabilities. The retarded person does not learn at a normal rate and has problems in adapting to what society expects. In addition, mentally retarded individuals often have other disabilities such as motor functioning, sensory handicaps, speech problems, and emotional and personality disturbances. There are four recognized levels of retardation: mild, moderate, severe, and profound.

What this means is that the retarded person may be totally independent, require total care or fall anywhere in between. For example, moderately retarded people require special education, usually vocational training to learn to work at simple tasks, and have the capacity to live happily and comfortably in a protected environment. Generally, the profoundly retarded individual is severely handicapped both physically and mentally, and requires constant attention and care.

About 126,000 mentally retarded babies are born each year in the United States. Some principal factors causing development defects are genetic, fetal disturbances during pregnancy, infectious, toxic, and nutritional difficulties during and after the birth period.

Miscarriage Also called spontaneous abortion, the death of a child born prematurely, without outside interference. When this is done with outside interference, it is called abortion.

Mongolism, Mongoloid See Down's Syndrome.

Muscular Dystrophy (MD) Several inherited diseases in which the muscles attached to the bones grow weaker and weaker, causing difficulties in movement and also causing deformity.

Neurologist A doctor specializing in finding and treating diseases and defects of the brain and central nervous system.

Obstetrician A doctor specializing in the care of pregnant women and in delivering babies.

Orthopedist A doctor who specializes in treating the spine, bones, joints, muscles, or any other parts of the skeletal system.

Ovulation The release of an egg (ovum) from the ovary (reproductive organ) of a female, which

occurs in most females about 14 days before menstruation.

Pediatrician A doctor who specializes in treating children.

Phenylketonuria (PKU) This inherited defect causes the body to be unable to breakdown or metabolize amino acids in meat, fish, eggs, cheese, and milk. It is a recessive trait caused by the lack of one enzyme, a substance necessary to digestion. It can lead to mental retardation, but diet and medical care begun at birth can result in a healthy child.

Physical Therapist A professional health care person who treats diseases and defects with heat, massage, or exercises.

Placenta The material surrounding the fetus that nourishes it, disposes of its wastes, and both connects and separates it from the mother.

Pregnancy The time between conception and birth, which usually takes about nine months. Certain symptoms may indicate that there are problems with the fetus:

- bleeding from vagina
- severe, continued nausea and vomiting (some of this is normal)
- continued, severe headaches
- swelling or puffiness of face, hands, feet, or ankles (not to be confused with normal weight gain in pregnancy)
- blurred vision, spots before the eyes
- marked decrease in amount of urine
- pain, burning in urinating
- chills and fever
- sharp, continuous abdominal (stomach) pains
- sudden gush of water from the vagina before the baby is due.

Premature See Low Birth Weight.

Prenatal Care Careful supervision by doctors, nurses, or midwives of the pregnant woman and unborn child. Over 25 percent of all women in America do not begin prenatal care until after the third month or do not have it at all. This increases the risk of death to child and mother, and of low birth weight, pregnancy complications, prematurity, and birth defects.

Recessive Trait A characteristic in a person that will pass on to the children only if the gene is passed on by both parents.

Rh Factor This is one of the factors in our blood. Most people have it, and their blood is called Rh positive. About 20 percent do not have it, and their blood is called Rh negative. This has no effect on the individual. It becomes important when a woman who is Rh negative is pregnant from a father with Rh positive blood. Their baby may die or have serious problems because the mother develops harmful substances in her blood. Any woman with Rh negative blood should remain aware of this and, when pregnant, receive the proper care to prevent the problems. She can also receive a vaccine three days after having a baby or an abortion. The vaccine can prevent the harmful substance from building up in her blood to threaten the health of any future babies.

Rubella Also called German Measles, this is a mild, contagious disease (not inherited) that lasts only a few days and causes a sore throat, fever, and rash. The baby of a pregnant woman with rubella can develop birth defects such as deafness, heart defects, eye diseases, damage to the central nervous system, and mental retardation. There is a vaccine that can make you immune to rubella, but it should not be given to anyone who is or might be pregnant. It should be given to all children before puberty. It prevents the spread of rubella by immunizing young girls and by keeping children from giving it to pregnant women. Girls and women who may be pregnant can and should be tested to see if they have rubella.

Sickle Cell Anemia An inherited disease, especially but not only among black people. About one in every 400 black children in America has it. It causes extreme tiredness, poor muscle tone, nausea, and sometimes early death. It is caused by an abnormality in the red blood cells, and it is a recessive trait. It can and should be detected and treated in children, adolescents, and adults. At present, however, there is no known cure for the disease. People who are carriers of the sickle cell trait may or may not have the disease themselves.

Species A basic biological unit identifying related animals or vegetables: human beings, dogs, and cats, for example. Ordinarily, reproduction can only occur within a species, not across species.

Spina Bifida A birth defect caused by heredity and environment. The infant's spinal canal is not formed properly. The defect varies in seriousness but can cause crippling and mental retardation. It can sometimes be detected before birth. About 6,200 children are born yearly with this defect.

Spontaneous Abortion See Miscarriage.

Stethoscope An instrument that enables a doctor to study sounds in the body. For example, a stethoscope allows a doctor to listen to the heartbeat of a baby before birth.

Syndrome A group of symptoms that, when taken together, usually characterize a disease. Syndromes are usually named after the scientist who discovers or first describes them: for example, Down's Syndrome.

Syphilis See STD.

Sexually Transmitted Disease (STD) Several diseases, including gonorrhea, herpes simplex II, and syphilis that are very infectious. They are spread by sexual and sometimes other intimate contact. Symptoms vary, but include pain or difficulty in urinating; sores and lesions near or on sexual organs, the mouth, nose, ears, or fingers; slight fever and persistent sore throat. Especially in women, there may be no recognizable symptoms in the early stages. All of these diseases can be detected, and all persons engaging in sex should be checked.

Treatment for syphilis and gonorrhea is simple and often free; these two diseases can usually be cured promptly. The tests and treatment can be had easily and in confidence. Yet these diseases are spreading rapidly, especially among teenagers. If untreated, they can lead to sterility, mental illness, blindness, and death.

Herpes simplex II is also becoming widespread. At present there is no known cure. The infection usually lasts about 10 to 14 days, and is charac-

terized by painful blisters. Half the infected babies die; half the survivors are physically or mentally impaired.

If you suspect that you have any of these diseases, it is important to get medical care immediately.

Tay-Sachs Disease This inherited disease is very rare, but always causes death. It usually appears shortly after birth, but may not emerge until age five or later. The child's eyes are marked with a red spot, and there is increased blindness and weight loss. It is recessive, and 85 percent of the cases are Jewish couples with ancestry in Eastern Europe.

Thalassemia Also known as Cooley's Anemia, this is an inherited disease caused by a blood abnormality. Those who inherit it from both parents need constant blood transfusions and usually die before age 20. Those who just carry the trait are only slightly affected.

Thalidomide This drug used to be prescribed to pregnant women to help them sleep or be calm. It produced severe deformities in the babies of these mothers. Because the U.S. Food and Drug Administration refused to allow it, thalidomide was never used in this country.

Therapy Treatment for any physical, mental, or emotional problem.

Toxemia A disease during pregnancy with symptoms that include high blood pressure, extremely heavy weight gain and unusual swelling, and, in extreme cases, convulsions and coma. Toxemia is thought to be caused by improper diet, and it can be corrected with proper care. If untreated, it can cause the death of the mother and the unborn child, or birth defects. Sometimes, pregnant women confuse weight gain with toxemia. Some weight gain and swelling is normal and desirable in pregnancy; the bloating caused by toxemia is clearly different and more serious.

Trait A characteristic. See Dominant and Recessive Traits.

Trimester A period of three months. Pregnancy is usually divided into three trimesters.

Uterus The womb; the place in the mother's body where the fetus grows and develops before birth.

Venereal Disease (see STD)

Womb (see Uterus)

Zygote The egg, after it is fertilized by the sperm.